Improving Work Participation of Young Adults with Physical Disabilities

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Het verbeteren van de arbeidsparticipatie van jongvolwassenen met lichamelijke beperkingen

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Chapter 1

General introduction

The main objective of this thesis is to design, evaluate and implement an evidence-based vocational rehabilitation intervention to improve the work participation of young adults with physical disabilities caused by a chronic condition.

This first chapter introduces the concepts of chronic physical conditions, work participation of (young) people with a chronic physical condition, and interventions to improve the work participation of young adults with a chronic physical condition. The chapter concludes with an outline of this thesis.

CHRONIC PHYSICAL CONDITIONS: DEFINITION AND PREVALENCE

Chronic diseases are the leading cause of disability worldwide (1). They often result in progressive physical disability and restrictions in daily activities and participation in society (2-5). Different terms are used to describe the concept, the most frequently used terms being chronic diseases, chronic illness, chronic disorder, chronic conditions, chronic health conditions and non-communicable diseases (1, 3, 6-9). Chronic conditions are defined by the World Health Organization (WHO) as requiring ongoing management over a period of years or decades, involving different health professionals, and extending into social care (3, 5). They cover a wide range of health problems and go beyond the definition of chronic disease, also including some communicable diseases, such as the human immunodeficiency virus (HIV), and physical disabilities and impairments that are not defined as diseases, such as musculoskeletal disorders (3). In this thesis, the term 'chronic condition' is used to indicate a broad scope, including physical disabilities and impairments, and the focus is on those chronic conditions causing physical disabilities, such as traumatic brain injury, neuromuscular diseases, rheumatoid arthritis or chronic respiratory diseases, also including childhood-

onset physical disability, such as cerebral palsy or spina bifida. Excluded are those chronic conditions causing mental or developmental disabilities (10).

Although the reported prevalence of chronic conditions varies, depending on the definition (i.e. which conditions or diseases are included) and the type of measurement (e.g. self-reported, or based on medical records), chronic conditions have a high prevalence. In 2012, over 30% of adults in Europe (and also in the Netherlands) reported a (self-declared) chronic condition and these rates are expected to increase in the future (11-13). The prevalence of physical and mental chronic conditions are not clearly distinguished and often co-occur; about 50% of persons (aged 18-65 years) with a chronic mental condition (18% of the population) also have a chronic physical condition (13). An increase in the prevalence of chronic conditions is evident in all age groups, and is the consequence of aging and increased longevity, early detection of chronic conditions and improved medical treatment together with improvement of medical records (3, 5, 6, 13). Improved medical treatment has resulted in an increasing number of young people with chronic conditions or physical disabilities living into adulthood, thereby challenging health care to support these young adults to make a successful transition into adulthood and to become autonomous individuals who participate in society (14-16).

In the Netherlands, over 30% of the working-age population (aged 16-64 years) reports a (self-declared) chronic condition, including physical and mental conditions; among young adults (aged 16-24 years) about 18% reports a chronic condition (11). Table 1 presents the rates for the prevalence of chronic conditions, including physical and mental conditions, and (some or severe) limitations in daily activities for Europe and the Netherlands, based on European statistics (11). In Europe, the proportion of persons with a chronic condition has remained stable over the last six years, and rates of chronic conditions in the Netherlands are relatively high. The increase in the rate of persons with some limitations and the decrease in persons with severe limitations might be (partly) explained by the changes in definitions used and in the methods of data collection in 2007 (11).

For the Netherlands, it is estimated that over two million persons (≥ 15 years) have a chronic physical disease or physical disability, of which about 76,000 are aged 15-25 years (17, 18). In 2013, the population of young adults with childhood-onset disabilities who are entitled to disability benefits because they are (partially) unable to work based on the so-called 'Invalidity Insurance Act for Young Disabled Persons' (in Dutch: *Wajong*), totalled about 239,000 persons, of which 84,000 persons were aged 15-25 years (19, 20). Of these young adults receiving *Wajong* benefits, 14% has a physical disability (about 12.000 persons) (17, 19, 21).

Table 1 Proportion (%) of the total population, working age population (16-64 years) and young adults (16-24 years) in Europe and the Netherlands reporting a chronic condition, some or severe limitations (based on Eurostat (hlth_silc_05, hlth_silc_06))

	Europe		The Netherlands	
	2012 %	2006 %	2012 %	2006 %
Chronic condition				
Total population	30.8	30.5	34.5	31.9
Working-age population	*23.1*	*23.6*	*29.7*	*28.1*
Young adults (16-24 years)	*10.2*	*10.6*	*17.8*	*18.2*
Some limitations in daily activities				
Total population	17.5	16.2	22.3	13.6
Working-age population	*13.0*	*12.1*	*19.0*	*11.7*
Young adults (16-24 years)	*5.6*	*4.8*	*11.1*	*5.6*
Severe limitations in daily activities				
Total population	8.9	7.8	5.8	8.2
Working-age population	*5.5*	*4.8*	*4.5*	*6.7*
Young adults (16-24 years)	*1.9*	*1.4*	*1.0*	*2.3*

Physical disabilities caused by a chronic condition may result in activity limitations or participation restrictions. In the Netherlands, about 30% of the people with a chronic condition causing physical disabilities reported problems with work participation (12, 18). The influence of a chronic condition on activities and participation may differ between diagnoses, or at different stages of the disease process (8). Common characteristics of chronic conditions include an unpredictable course and day-to-day variability of symptoms, challenging the individual to manage the impact of the condition on physical, psychological and social functioning and to adjust their daily activities to the altered and still altering situation (2, 22). The most frequently reported causes of activity limitations and participation restrictions resulting from chronic conditions are fatigue, pain and physical limitations (4, 22-24).

WORK PARTICIPATION OF PERSONS WITH A CHRONIC PHYSICAL CONDITION

Although participation is an important long-term outcome of rehabilitation, the concept of participation is not clearly defined (25-27). According to the International Classification of Functioning (ICF), the WHO framework for measuring health and disability, participation refers to involvement in a life situation and

involves taking part in activities with others or in varying environments, and participation restrictions extend beyond experiencing problems in the performance (´execution´) of daily tasks or activities. Participation emerges at the intersection of the person and the environment and includes fulfilling social roles and having responsibilities, maintaining interpersonal relationships, performing meaningful and productive activities, as well as independent living, and making decisions and life choices (26-28).

One of the domains of participation is work, also referred to as employment or productivity. Participation in work is important for individuals, offering income and financial independence, social relationships, social status, daily rhythms and, often, meaning in life. According to the WHO, being able to work productively and fruitfully is important for mental health (29). Enablement of persons with disabilities to attain and maintain their maximum vocational ability is included in the United Nations convention on the rights of persons with disabilities (30). To emphasize participation, in this thesis we use the term 'work participation', rather than employment.

Chronic physical conditions often result in temporary or permanent health-related problems in work participation, such as (involuntary) part-time job, lower productivity, sick leave, higher job turnover, loss of earnings, denied seniority or promotion, job loss, and early retirement or unemployment (5, 31-33). Finding and keeping a job is reported to be a major problem for people with a chronic condition or physical disability (4, 24). Frequently reported problems of working people with a chronic condition are difficulties meeting work demands (e.g. work hours, work pace), difficulties to perform tasks requiring accuracy or precision, mobility at the workplace, transportation to the workplace or accessibility of rooms or buildings, relations with colleagues and balancing work and home-life (22, 23, 32, 34). Although chronic conditions vary substantially regarding their course and burden, one study found that the labour market position of persons with a chronic condition was primarily related to health problems that could be considered common consequences of a chronic condition, such as disease duration, the episodic nature and frequency of symptoms, pain, fatigue, and functional disabilities (4).

As a consequence, the employment rates among people with a chronic condition or physical disabilities are low compared to the general population (4, 8). In the Netherlands, overall, employment rates of people with a chronic condition range from 25-49% (8, 32, 35), compared to 67-75% of the working-age population (16-65 years) (11, 36). Generally, employment rates are lower among women (32). Employment rates for people with a chronic condition differ for different age groups and tend to decrease as age increases: in the Netherlands, employ-

ment rates of 48% (15-39 years), 38% (40-54 years) and 16% (55-64 years) are reported, compared to 66% (15-39 years), 80% (40-54 years) and 49% (55-64 years) in the general population (8). In addition to the lower employment rate, people with a chronic condition more often work part-time (5, 32). In the Netherlands, people with a chronic condition work on average 25 hours/week, compared to 34 hours/week in the general population (32).

Comparison of employment rates between countries is difficult, since employment rates are affected by institutional frameworks, such as disability pension regulations (37). Moreover, different definitions of employed persons are used: Statistics Netherlands defines being employed as performing paid work for ≥ 12 hours/week, while most other resources (e.g. European statistics) define employed as performing work for pay or profit for at least 1 hour/week. In this thesis, we define work participation as working ≥ 12 hours/week, according to Statistics Netherlands, to allow comparison of the employment rate of study samples with the general Dutch population of the same age (www.cbs.nl). For young adults entering the labour market, we included (paid and) unpaid employment for ≥ 12 hours/week, because it contributes to fulfilling societal roles and offers work experience and entrance to the work force that could facilitate achieving paid employment. Unpaid employment or voluntary work can also be considered as an indicator of participation based on the ICF (35, 38-40).

The work participation of people with a chronic condition or physical disability is a growing concern in health care and society (3, 33). Recently, government policies emphasize inclusion and active participation in society, and have shifted the focus towards a person's ability, rather than a focus on disability and 'protective' approaches that encourage access to disability benefits (19, 41).

WORK PARTICIPATION OF YOUNG ADULTS WITH A CHRONIC CONDITION OR PHYSICAL DISABILITIES

Research has mainly focused on (return to) work participation of adults with a chronic physical condition, while less is known about young adults with a chronic condition causing physical disabilities that were diagnosed before they enter the labour market (42, 43). These young adults with childhood-onset disabilities who enter the labour market, face different barriers than adults with a chronic condition who have already developed a vocational career (42).

Different terms and age limits are used to describe youth or young adults transitioning to adulthood. Recently, the term 'emerging adulthood' was introduced by Arnett from a developmental perspective, lasting from about age 18 years

(marked by high school graduation) to at least age 25 years, arguing that the transition to adulthood has become so long in industrialized societies that a new phase of the life course has emerged in between adolescence (age range 10-19 years) and young adulthood (from age 25 years) (44). Although recent understanding suggests the use of the term emerging adults, in this thesis we use the term 'young adults', which refers to the age range 16-25 years. These age limits were selected based on the literature and on the domain of transition that was studied (16, 36, 45, 46). For the transition to employment the minimum age of 16 years was chosen since, in the Netherlands, compulsory education ends at age 16 years; in addition, young people in the Netherlands enter the labour market early, compared to their peers in some other European countries. In the Netherlands, at age 16 years at least half of young people are in the labour market (including all those who do any work for pay or profit for at least 1 hour/week, according to a broad European definition of employment) (46).

In the process of transition to adulthood, one of the challenges is to find a job. At this young age the process of finding and keeping a job takes place in the context of transitions in other domains of participation such as independent living, developing intimate relationships, leisure, financing and transportation (45). Employment plays an important role in independence and autonomy; it provides financial independence to young adults and is important for psychological wellbeing, by structuring the day, providing social interaction and meaningful contribution to society, and developing self-identity (43, 47, 48). However, young adults with a chronic condition or physical disabilities experience considerable difficulties in the area of employment (14, 15, 19, 43, 47).

Reported employment rates for young adults with a chronic condition or physical disabilities vary but, overall, employment rates of about 30% are reported in both Europe and the USA (11, 40, 49). For the Netherlands, employment rates of 39-45% are reported among young adults with physical disabilities (13, 50, 51), compared with 64-72% in the general population of the same age (11, 13). Apart from differences in the severity of physical disabilities or between country differences, differences in reported proportions may result from different definitions for being employed (≥ 1 or ≥ 12 hours/week) and/or use of different age ranges (15-24 years versus 16-25 years).

Young adults with physical disabilities perceive themselves as strongly restricted in employment opportunities and would welcome support to help them find suitable employment (15, 47). In addition to finding a job, maintaining employment (e.g. for more than one year) is an important obstacle for young adults with disabilities (52). In the Netherlands, of the young adults with *Wajong* benefits 25% is employed, although a minority is declared fully unfit for work (19, 21).

Also, studies among young Dutch adults with cerebral palsy and spina bifida have shown that 30-50% of the participants reported problems regarding employment (15, 45, 47). Reported problems include finding employment, being offered work that was physically or mentally too demanding, transportation facilities, accessibility of buildings, toilet space, and a reluctant attitude among employers; the most frequently indicated barrier was transportation (15, 47, 53, 54).

INTERVENTIONS TO IMPROVE WORK PARTICIPATION OF YOUNG ADULTS WITH PHYSICAL DISABILITIES

Studies addressing interventions to improve work participation generally focus on employees with a chronic physical condition or physical disability who have work experience and are often able to return to a previous job and previously established workplace relationships. Young adults entering the labour market are in a different situation because they have to find employment, establish workplace relationships and balance work with other activities and roles. In young adults with a chronic condition causing physical disabilities, support to improve their work participation involves multiple stakeholders, including the young adult, parents, teacher(s), therapist(s), physician, employer, social security institute (in the Netherlands: UWV), local authorities, and a job coach or vocational counsellor (19, 55, 56). Currently, there is no evidence to support the effectiveness of interventions to improve work participation of young adults with physical disabilities caused by a chronic condition. Also, information on opportunities for young adults with physical disabilities to participate in work is very limited (19).

Vocational rehabilitation offers various forms of training, counselling, and placement to support persons with disabilities to participate in the competitive labour market (30). However, evaluation of vocational rehabilitation is difficult due to the wide range of different services that are provided to individuals, and in general, its effects are still largely unknown.

Rehabilitation interventions provided by occupational therapists frequently use the model of human occupation (MOHO) as a theoretical framework (57). Interventions based on the MOHO emphasize motivation, conceptualized as an interaction between personal interests, values and personal causation (referring to self-efficacy), and the development of routines, habits and skills to perform productive occupational roles (58). Vocational interventions based on this model have a positive impact on improving vocational outcomes in clients with different chronic conditions (57). However, evidence for the effectiveness of these programs from controlled studies is still lacking.

A vocational intervention to assist people with severe (primarily intellectual and developmental) disabilities to find and maintain competitive employment, is supported employment (SE) or individual placement and support (IPS) (59). SE uses a ´place then train´ model offering ongoing support services by a job coach and applies the principles of empowerment and individualized, community-based support (59). In the Netherlands, SE was introduced in 1990 and contributed to a shift in focus on the ability instead of the disability regarding employment on the open labour market for persons with disabilities (60). However, there is limited evidence suggesting that supported employment is effective in improving vocational outcomes in adults with severe mental illness and people with learning difficulties (61, 62).

The general employment agencies have offered their services to persons with disabilities, since the reintegration market for support to persons with physical disabilities was privatised in 2002 (63). Generally, two types of instruments can be applied: reintegration trajectories and reintegration facilities. Reintegration trajectories are tailored to individual needs and aim to help people receiving disability benefits get (back to) work; they may include training or education. Reintegration facilities may include on-the-job coaching, transportation, facilities or adaptations in the work environment, or wage dispensation (63). Private agencies offering vocational services provide guidance and support for persons who are distanced from the labour market, using methods affecting labour supply (the client), demand (the employer) and the match between both. The main methods to influence the client are activation, guidance, facilitation, exploring identity, information, education, and social appreciation or sanctioning; methods to influence the supply of employers are information, mediation and (financial) compensation; and methods to influence the match between supply and demand are information and connection (64). Since 2004, persons are allowed to design an 'Individual Reintegration Plan' (IRO) within a standard reintegration budget, offering more freedom of choice (63).

For people with physical disabilities, barriers to the labour market can also be addressed by laws and regulations, or social protection (30). In the Netherlands, the government aims to encourage work participation of young adults with a childhood-onset chronic condition or physical disability (before age 18 years) who are entitled to *Wajong*-benefits by offering income support and employment support (19, 65). They can apply for income support, support services to find employment and, if necessary, support at the work place, such as job coaching or a modified workplace. Young adults who are capable of working in competitive employment are referred (if necessary) to a reintegration consultancy for job placement and training (19).

Since the start of this research project, two other initiatives have been realized in the Netherlands to support young adults with a chronic condition to find employment, i.e. 'Emma at work' and 'Brains4U'. 'Emma at work' is a temporary employment agency specialized in supporting young adults (15-25 years) with a chronic condition to achieve employment and to earn wages that was established in 2006 (17). Gaining work experience at a younger age in temporary jobs, summer jobs or in a regular job should enhance their chances on the labour market on the long term (www.emma-at-work.nl). Since 2012, the program 'Brains4U' has offered support to young adults (18-45 years) with traumatic brain injury to integrate in suitable and sustainable paid employment in The Hague. Elements of the program are a participation assessment, empowerment sessions and a buddy program. After assessment, a young adult is matched with an employer, who fulfils the role of a buddy or mentor during a period of (at most) 6 months (www.brains4u.nl).

The research project presented here was initiated due to the lack of interventions to support young adults with physical disabilities to achieve employment and the start of an outpatient clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre, combined with increasing attention for participation of young adults with disabilities. The design, realisation and implementation of an intervention aiming to improve the work participation of young adults with physical disabilities was considered very important for young adults, and also relevant for society due to a possible decrease in disability benefits for young adults and the possibility of 'return in investment' for costs of the intervention. Since participants are young, the financial benefits of paid employment may have long-lasting effects, both increasing their autonomy and decreasing the financial burden on society.

OUTLINE OF THE THESIS

To design and evaluate a vocational rehabilitation intervention to improve the work participation of young adults with physical disabilities caused by a chronic condition, the following research questions are addressed in this thesis:

1. What evidence is available regarding effective interventions to improve the work participation of persons with a chronic physical condition?
2. How does work participation develop in young adults with cerebral palsy during their transition to adulthood?

3. Is the modified Dutch-language version of the work limitations questionnaire an intelligible, reliable and valid instrument to assess work limitations among working persons with a chronic physical condition in the Netherlands?
4. Is it feasible to implement a new vocational rehabilitation intervention to improve the work participation of young adults with physical disabilities caused by a chronic condition in an outpatient rehabilitation clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre in Rotterdam?

For the design and evaluation of the intervention three preliminary studies were performed.

Chapter 2 describes a systematic review of the literature to evaluate the characteristics and effectiveness of interventions aiming to improve work participation of adults with chronic physical conditions.

To explore the target group for the intervention and the problems with work that they experience, **Chapter 3** describes a longitudinal study documenting the development of work participation over a 4-year period in young adults with cerebral palsy transitioning into adulthood; moreover, work limitations and situational or health barriers to employment experienced by employed persons with cerebral palsy were investigated.

Chapter 4 examines the intelligibility and psychometric properties of the modified Dutch-language version of the Work Limitations Questionnaire (WLQ-mdlv) among employed adults with various chronic (physical) conditions in the Netherlands.

Then, we describe the design, evaluation and implementation of a new vocational rehabilitation intervention for young adults with physical disabilities caused by a chronic condition. **Chapter 5** evaluates the feasibility of the intervention to improve the work participation of young adults with physical disabilities, addressing implementation and costs, as well as its preliminary effectiveness.

Chapter 6 describes how occupational performance of participants of the intervention changed over time, addressing work, as well as self-care and leisure activities. In addition, we explore differences between young adults who were employed and unemployed after the intervention.

Finally, **Chapter 7** discusses the main findings of this thesis within the context of the current literature, reflects on methodological considerations, discusses implications for clinical practice, and makes recommendations for future research.

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Chapter 2

Effectiveness of interventions to improve work participation in adults with chronic physical conditions: a systematic review

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ABSTRACT

Objective: To evaluate the characteristics and effectiveness of interventions aiming to improve work participation in adults with chronic physical conditions, excluding back disorders.

Methods: A systematic search in Medline, Cinahl, Cochrane, Embase and PsycINFO up to November 2013 identified 3026 potentially relevant studies. In total, 25 studies were included and assessed for their methodological quality. For the outcomes of interest we assessed the strength of the body of evidence using the Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE).

Results: Interventions addressing work participation varied widely regarding delivery characteristics and content. Overall, inclusion of group treatment, a multidisciplinary approach and a high frequency, often combined with a short duration (<8 weeks), were more often used. Most studies addressed the outcome work status. Evidence was found for effectiveness of interventions on work participation, but the quality of the evidence was rated low regarding work productivity and very low regarding work status and work attitude. Results were irrespective of the specific condition, except for better effectiveness in chronic pain and musculoskeletal disorders.

Conclusions: This overview shows that interventions seem to contribute to improved work participation in adults with chronic physical conditions, but the quality of the evidence was rated very low to low. The lack of common characteristics in effective interventions suggests that addressing work participation within the rehabilitation of persons with a chronic condition, using systematic and targeted interventions, seems beneficial to improve or sustain work participation, regardless of specific intervention characteristics and diagnosis.

INTRODUCTION

Advances in medical technology, management of infectious diseases, better prevention and improved living conditions have resulted in an increased prevalence of chronic conditions that require ongoing medical attention and management (1-3). In Western countries, proportions of adults with a chronic condition or long-lasting health problem range from about 30% to over 50%, depending on the definition of chronic conditions and measurement used (self-reported or medical records) (1, 4, 5). Among the working-age European population (16-65 years) 23% reports a chronic condition or disability (5).

Chronic conditions refer to disorders that are persistent or have long-lasting effects, often resulting in physical disabilities and restrictions in daily activities, participation, quality of life and wellbeing (1, 2, 4, 6). Participation restrictions may include temporary or permanent health-related problems in work participation, such as sick leave, job loss or unemployment (6-8). People with a chronic condition are less likely to be employed full time, and more likely to be unemployed than those without a chronic condition. About 30% of employees with a chronic condition experiences problems with employment related to their condition; e.g. finding or maintaining a job, and difficulties to perform job demands, job content or working conditions (8-10).

Employment rates among people with a chronic condition or physical disabilities are low compared to the general population (9, 11-13). In the Netherlands, only 25-35% of the working-age people (16-65 years) with a chronic physical condition or physical disabilities has a paid job for at least 12 hours a week, compared to 67% of the general population (8, 14). In addition to lower work participation, people with a chronic condition work (on average) 25 hours a week, compared to 34 hours in the general population (8). Due to the growing number of people with a chronic condition and their problems with employment, their work participation is a growing concern in society (2, 9, 11, 15). Although chronic physical conditions vary in their course and consequences, they often result in temporary or permanent health-related problems in work participation, that can be considered common consequences of a chronic condition (11). Knowledge is lacking about which (generic components of) rehabilitation interventions are effective to improve work participation of persons with a chronic physical condition, irrespective of the specific diagnosis.

Intervention studies in this field have not yet been systematically reviewed, except for interventions in persons with back disorders (16-18). This systematic review evaluates the characteristics and effectiveness of rehabilitation interventions aiming to improve work participation of adults with a chronic physical

condition, other than back disorders. Focusing on work participation, a heterogeneous approach with respect to diagnosis is used, including various chronic physical conditions. Intellectual, mental or psychiatric disorders are excluded because they may require different interventions.

METHODS

To structure this systematic review and to improve the quality of reporting we used the checklist of Preferred Items for Systematic Reviews (PRISMA statement) (19).

Search strategy for identification of studies

A systematic extensive electronic search was conducted in the databases Medline, Cinahl, Cochrane controlled trials register, Embase and PsycINFO up to November 2013. To identify relevant studies a broad search strategy was used built on the following components: 1) Population: patients with chronic conditions causing physical limitations or disabilities, using the terms: "Chronic Disease"[MeSH] OR "Disabled Persons"[MeSH] OR chronic OR disability OR disabilities; combined with the terms: NOT (psychiatric OR mental) to exclude studies addressing psychiatric or mental chronic disorders; 2) Intervention: rehabilitation interventions, using the terms: "intervention studies" [MeSH] OR program OR training OR education OR rehabilitation OR therapy OR multidisciplinary; 3) Outcome: work participation, using the terms: "Work"[MeSH] OR "Employment"[MeSH] OR "Employment, Supported"[MeSH] OR "Occupations"[MeSH] OR job OR employment OR vocation (20).

The three strings were combined to achieve the final results. To identify high quality evidence, we used the search strategy for randomised controlled trials (RCTs) and controlled clinical trials recommended by the Cochrane collaboration (21). The search strategy was adapted according to the particular database, using database thesauruses to identify relevant variations of these terms. In addition, the reference lists of the identified original papers were checked for additional relevant studies.

Selection of studies

First, one reviewer (JV or MB) screened the titles against the inclusion criteria and discarded obviously irrelevant publications. Three authors (JV, MB, PR) then independently screened the titles and abstracts of the remaining studies for inclusion. Full-text copies of selected papers were obtained and two authors (JV,

MB) independently examined potentially relevant studies. If inclusion criteria were not fulfilled, papers were excluded. Any discrepancies were resolved by a third reviewer (HM).

Studies were included for assessment of methodological quality and data extraction if they met the following inclusion criteria: 1) study design: RCT or controlled study; 2) participants: working-age adults (18-65 years) with a chronic condition causing physical limitations; chronic condition being defined as a physical condition, other than back disorders, lasting ≥ 3 months, or a physical condition that is specified and can be categorised as long-lasting based on disease characteristics (e.g. rheumatoid arthritis); 3) intervention: rehabilitation intervention containing specific elements to improve work participation of the participants (excluding surgery, medication); and 4) outcome: work participation, addressing work status, work productivity or work attitude.

Assessment of methodological quality of included studies

Pairs of authors (JV or MB with one of the other authors) independently appraised the methodological quality of all studies included in the review, using the Cochrane criteria list for the methodological quality assessment (22). The following two items were added from the criteria list of the Cochrane Back review group: '*Were the index and control intervention explicitly described*?' and '*Were the outcome measures relevant for work participation?*' (23). The total criteria list consisted of 13 items; each scored with ´yes´ (2 points), 'no' (0 points) or 'don´t know' (1 point) (24). Item scores were summed to a total score ranging from 0-26 points. Studies were considered to be of high methodological quality if at least six criteria were scored as 'yes' and the total score was ≥ 14 points; studies with a total score of ≤ 13 points were considered as low methodological quality. Any disagreements regarding scoring were discussed until consensus was achieved.

Data extraction

Data extraction was systematically performed by two independent reviewers (JV and MB) using a pre-designed data extraction form containing study characteristics, patients, delivery characteristics of interventions, content of interventions, outcome measures and results.

With regard to delivery characteristics of interventions, we examined three aspects:

- Treatment, distinguishing between individual treatment and group training.
- Professionals, distinguishing between a monodisciplinary or a multidisciplinary approach, meaning two or more professionals from different disciplines provided the intervention.

- Duration and frequency, distinguishing between interventions with short (< 8 weeks), moderate (8-12 weeks) or long duration (> 12 weeks), based on median (mean) duration of interventions of 8 (12) weeks of included studies; and high frequency (two or more sessions a week) or low frequency (one session a week or less).

With regard to content, interventions were classified in one of three categories, according to the functional domain that was primarily targeted to improve work participation:

- Physical: interventions aiming to improve physical functioning with a focus on exercise training (addressing endurance, strength, movement), skill training, graded activity or work hardening;
- Cognitive-behavioural: interventions aiming to change behaviour or perception with a focus on coping, problem solving, goal setting, cognitive skills, communication, stress management or empowerment;
- Vocational: interventions aiming to improve vocational functioning, addressing job searching, job interview skills, specific work training, job placement, vocational counselling or work place visits.

To specify the primary outcome work participation, we investigated three categories:

1. Work status, reported as dichotomous outcome (yes/no) presenting the proportion of the study sample achieving return to work, employment or job maintenance;
2. Work productivity, reported as continuous outcome presenting work productivity (hours worked) or duration of sick leave;
3. Work attitude, reported as continuous outcome presenting scores on work readiness (action to find a job), employment activities, employability or self-efficacy at work.

Other outcome measures from the selected articles were not included in the review to enable comparison of effectiveness across studies.

Data analysis

Due to the variety of interventions and patients we used several strategies for data analysis. First, we described the delivery characteristics and treatment components of interventions, as well as the targeted patient population.

Second, for the outcomes of interest we assessed the strength of the body of evidence using the Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE) approach, as recommended in the Cochrane Handbook 5.1 (21). The GRADE approach involves separate ratings for quality of evidence for each outcome as high, moderate, low, or very low. RCTs start with a

high rating, that may be modified downwards (or not), across studies, with respect to each of five factors: 1) study limitations, that were rated based on assessment of methodological quality of studies, 2) inconsistency in results (heterogeneity in magnitude of effects among studies), 3) indirectness of evidence, considering indirect comparison and differences in populations, interventions and outcomes of interest between studies, 4) imprecision of results, relating to wide confidence intervals (CI) that include both important benefits or no important effects within the 95% CI, and 5) likeliness of publication bias (25-29). For each outcome, we categorised the quality of the body of evidence as "high" for RCTs without downgrading, "moderate" for single downgraded (i.e., rated down for one of five factors) RCTs, "low" for double downgraded (i.e., rated down for two factors) RCTs, or "very low" for triple downgraded (i.e., rated down for three factors or more) RCTs. A random effects model analysis was applied to take into account the statistical heterogeneity of the studies. For the dichotomous outcome work status, the risk ratio was used to compare effect sizes. Risk ratios describe the probability with which a positive outcome (e.g., return to work) will occur in the intervention group and are easier to interpret than odds ratios (21, 27). For the continuous outcomes work productivity and work attitude, the standardised mean difference was used because various measurement scales were used across studies to assess these outcomes (21). For work productivity, mean values for reported sick leave were multiplied with -1 to correct for differences in direction of the scale. If provided, outcomes at 52 weeks (1-year) follow-up were used for the analyses. If otherwise, duration of follow-up in weeks was added in the study reference (e.g., Macedo et al. 2009_26). We checked for publication bias by constructing a funnel plot.

Our final step was to examine the effectiveness of the interventions for various chronic conditions that the studies addressed. Pooled estimates could not be calculated because of the clinical and statistical heterogeneity between the studies. Review Manager 5.2 was used to perform analyses and to generate forest plots (30).

RESULTS

Literature search and quality assessment

A literature search in electronic databases up to November 2013 identified 3843 potentially relevant studies. After removal of duplicates, the literature search resulted in 3026 hits. Two authors scanned all titles for relevance and excluded 2937 records based on title or abstract because they did not fulfil the

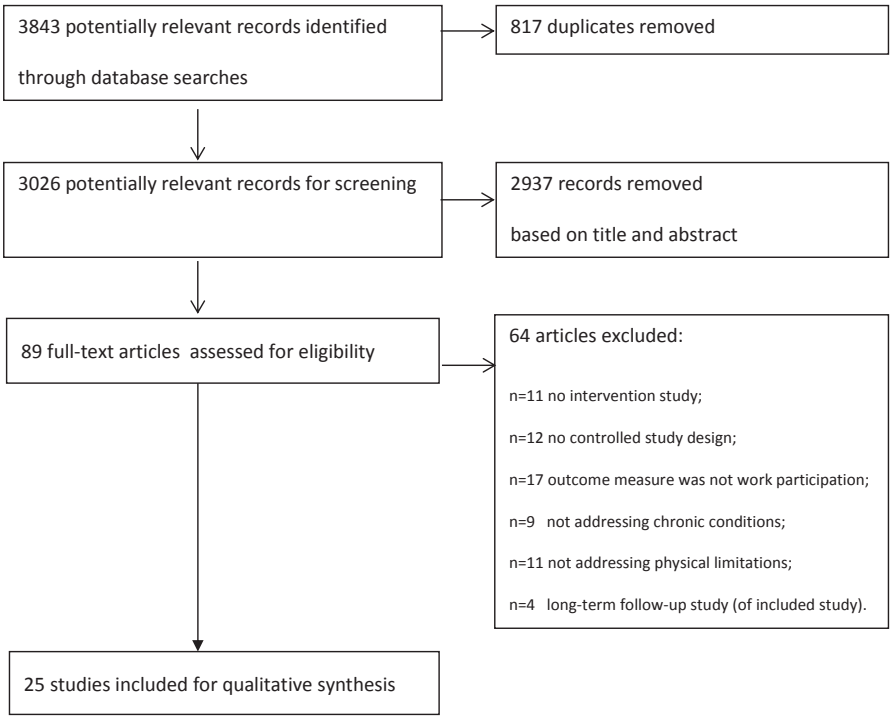

Figure 1 Flowchart showing the identification and selection of studies

inclusion criteria, resulting in 89 relevant studies that were screened full-text for eligibility. The literature search and decisions on included/excluded studies are shown in Figure 1; 25 studies were included for qualitative synthesis. Results of the methodological quality assessment of the included studies are presented in Table 1.

Of all studies, 22 were published within the last 14 years and three were published between 1991 and 1999. The studies were conducted in a broad variety of countries: the USA (n=8); Hong Kong (n=3); Norway (n=3), Sweden (n=3), the Netherlands (n=3); Canada (n=1), Germany (n=1), New Zealand (n=1), Switzerland (n=1) and the United Kingdom (n=1).

Participants

The included studies addressed work participation in patients with chronic pain (n=8), musculoskeletal disorders (MSD) (n=5), rheumatoid arthritis (RA) and other rheumatic diseases (n=4), traumatic brain injury (TBI) (n=3), populations of various chronic physical diseases (n=3), spinal cord injury (SCI) (n=1) and human

Table 1 Quality assessment of the included studies

Study:	Adequate method of randomization?	Was treatment allocation concealed?	Were groups similar at baseline regarding most important prognostic indicators?	Were index and control interventions explicitly described?	Was the patient blinded to the intervention?	Was the care provider blinded to the intervention?	Were cointerventions avoided or similar?	Was the compliance acceptable in all groups?	Was the outcome assessor blinded to the intervention?	Were the outcome measures relevant?	Was the drop-out rate described and acceptable?	Was the timing of the outcome assessment in all groups similar?	Did analysis include an intention-to-treat analysis?	Total points	Methodological quality
ALLAIRE et al. 2003 (37)	+	+	+	+	-	-	?	?	?	+	+	+	+	19	High
ANDERSON et al. 2007 (45)	+	+	-	+	-	-	-	?	+	+	-	+	+	15	High
BRATTBERG et al. 2006 (39)	+	?	+	+	-	-	+	?	+	+	+	+	+	20	High
DE BUCK et al. 2005 (32)	+	+	+	+	-	-	?	+	+	+	+	+	+	21	High
LI et al. 2006 (46)	+	+	?	+	-	-	?	?	+	+	?	+	-	16	High
LI-TSANG et al. 2008 (47)	-	-	+	+	+	-	?	+	+	+	+	+	?	18	High
MACEDO et al. 2009 (33)	+	+	+	+	-	-	+	+	-	+	+	+	?	19	High
MARHOLD et al. 2001 (48)	?	?	?	+	-	-	+	?	+	+	+	+	?	17	High
MARTIN et al. 2012 (49)	?	?	+	+	-	-	?	-	?	+	+	+	+	16	High
MEYER et al. 2005 (50)	+	+	+	?	+	-	+	+	+	+	+	+	?	22	High
OTTOMANELLI et al. 2012 (34)	+	+	+	-	-	-	?	+	-	+	+	+	+	17	High
SALAZAR et al. 2000 (51)	+	+	+	-	-	-	-	?	+	+	+	+	+	17	High
SKOUEN et al. 2006 (52)	+	+	?	+	-	-	+	?	+	+	+	+	-	18	High
STORRÖ et al. 2004 (42)	-	-	+	+	-	-	?	?	+	+	+	+	-	14	High
Cheng et al. 2007 (31)	?	?	+	?	-	-	+	?	?	+	+	+	-	15	Low
Detaille et al. 2013 (40)	?	?	+	?	-	-	?	+	?	+	+	+	-	15	Low
Feuerstein et al. 1993 (53)	-	-	-	+	-	-	?	?	?	+	+	-	-	9	Low
Haffey et al. 1991 (36)	-	-	-	?	-	-	?	?	+	+	+	?	-	10	Low
Ipsen et al. 2012 (41)	+	?	+	-	-	-	?	-	+	+	-	+	-	11	Low
Kendall & Thompson 1998 (43)	-	-	-	?	-	-	?	?	+	+	+	-	-	9	Low
Marnetoft & Selander 2000 (54)	-	-	-	+	-	-	+	?	?	+	+	-	-	10	Low
Niemeijer et al. 2010 (44)	-	-	+	+	-	-	?	?	?	+	-	-	?	10	Low
Schlademann et al. 2007 (38)	+	?	+	-	-	-	?	?	?	-	+	+	+	14	Low
Sullivan et al. 2006 (35)	-	-	?	+	-	-	?	?	+	+	+	+	-	13	Low
Varekamp et al. 2011 (55)	+	?	-	+	-	-	-	+	-	+	-	+	+	13	Low

Criteria: + ='yes' (2 points), - = 'no' (0 points), ? = 'not described/don't know' (1 point), based on updated method guidelines for systematic reviews (Van Tulder et al. 2003). High-quality studies are indicated in capital letters.

immunodeficiency virus (HIV) (n=1). Ten small studies had ≤ 73 participants and the remainder included 94-279 participants.

Characteristics of interventions

Table 2 presents an overview of the study and intervention characteristics, addressing delivery characteristics and content of interventions.

Delivery characteristics of interventions

With regard to treatment, eight interventions were characterised by individual treatment (31-38) and 17 interventions by a group program (39-44), in 11 interventions combined with individual treatment (45-55).

Fourteen interventions applied a multidisciplinary approach, including two or more different healthcare professionals in eight interventions (i.e., physician, physiotherapist, occupational therapist, psychologist, social worker) (32, 35, 38, 42, 43, 50, 52, 54). Five of these interventions included vocational professionals, such as a vocational counsellor or job coach (36, 46, 49, 53, 55). Eleven interventions used a monodisciplinary approach (31, 33, 34, 37, 39-41, 44, 45, 47, 48).

Duration of the interventions ranged from 3 weeks to 18 months, frequency ranged from two sessions in 5 months to a daily structured program, and total intervention time ranged from 3 to 140 hours. Ten interventions had a short duration, lasting 3 to 8 weeks (31, 40, 42, 46, 47, 49, 52, 53); of which nine had a high frequency and one a low frequency (40). Six interventions had a moderate duration of 8-12 weeks (32, 35, 41, 44, 50, 51), of which three had a high frequency and three a low frequency (32, 35, 41). Nine interventions had a long duration, lasting ≥ 12 weeks (33, 34, 36, 37, 39, 45, 48, 54, 55), of which seven had a low frequency and two a high frequency (36, 54).

Concerning delivery characteristics, inclusion of group treatment (n=17), a multidisciplinary approach (n=14) and a high frequency (n=14) were more often used.

Content of interventions

All 25 interventions consisted of multiple treatment components, such as education (n=21), physical exercise training (n=13), skills training (n=13), work training (n=12), counselling or guidance (n=9); ten interventions included individual assessment.

Seven interventions were classified as (primarily) targeting physical functioning to facilitate change and to improve work participation (31, 35, 38, 42, 45, 52, 53), eight interventions as targeting cognitive-behavioural functioning (39-41, 43, 44, 46, 48, 55) and ten interventions as targeting vocational functioning

Table 2 Characteristics of the included studies and interventions

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS						
Study	Method				Delivery characteristics			Intervention content			
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
ALLAIRE et al. 2003	N=242; Rheumatic disease	job loss; Interview	Printed materials only	No significant differences between IG and CG at 12 months. After 42 months differences between groups were significant (p = .03) (positive trend)	I	Rehabilitation counsellor	Two 1.5hr sessions within 5 months (total 3 hrs)			+	Job retention vocational rehabilitation intervention, addressing job accommodation (work barriers and solutions), vocational counselling and guidance.
ANDERSON et al. 2007	N=52; Chronic pain	Work status (RTW); Registration of work status	Usual care (multi-modal treatment during 4 weeks)	No significant differences between groups (p=0.09); IG: 65% vs CG 35% RTW after 12 months (positive trend)	GI	Physical therapist (Others: not described)	Multimodal training (UC) followed by 18x training group during 1.5 yrs (total ± 27 hrs)	+			Multimodal treatment for 4wks (UC) followed by training group based on Psychomotor Physiotherapy (NPMP), emphasizing functional movements, body awareness, relaxation ability, and balance and incorporating cognitive behavioural therapy.
BRATTBERG et al. 2006	N=60; Chronic pain or burn-out	Work capacity; Hours worked per week.	Waiting list	More persons in IG had improved their work status compared to CG (p=.007). Significant group differences in work capacity after 12 months (52% in IG vs 13% in CG) (p = 0.005)	G	Therapist/teacher and expert-patient (role model)	20 weeks with weekly sessions (total ± 20 hrs)		+		Pain workshop internet course, addressing obstacles to change, expectations and disappointments, self-knowledge, self-destructive behaviour, setting limits, stress management, strengths and weaknesses.
Cheng et al. 2007	N=94; Musculoskeletal injuries	RTW; Interview	Clinic based work hardening	Higher RTW rate in IG than in CG after 4 wks, (71% vs. 37%, p= 0.01)	I	Job coach (Others: not described)	4 weeks with 3 sessions per wk (total ± 12 hrs)	+			Workplace-based work hardening training. Job-specific activities, ergonomic education.
DE BUCK et al. 2005	N=140; Rheumatic disease	Job loss; Record of work status.	Usual care	No difference between groups in proportion of patients with job loss at any time point up to 24 months	I	Rheumatologist, social worker, physical therapist, occupational therapist, psychologist.	At least 2 (median 3) visits in 4-12 wks (total ± 3 hrs)			+	Multidisciplinary job-retention vocational rehabilitation using counselling and guidance, addressing identification of resources for adapting work environment, promotion of work self-efficacy.

Table 2 Characteristics of the included studies and interventions (continued)

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS					
Study	Method				Delivery characteristics			Intervention content		
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
Detaille et al. 2013	N=104; Chronic somatic disease	Self-efficacy (SE) and Self-management (SM) at work; Questionnaires	Usual care	Self-efficacy and SM (importance) did not differ significantly after 8 months; attitude towards SM (enjoyment) improved	G	Two trainers (1 master-trainer and 1 trained lay-leader with a chronic condition)	6 weeks with weekly 2.5-hr sessions; (total 15 hrs)		+		Self-management program for workers with a chronic somatic disease, addressing skill mastery and goal setting, coping, positive reframing, communication, work situation.
Feuerstein et al. 1993	N=34; Musculoskeletal disorders	RTW; Interview, WRQ2	Usual care	After average 17 months, significantly more persons in IG than CG returned to work or were in vocational training ($p<0.05$)	GI	Physical therapist, psychologist, work conditioning technician, vocational counsellor	4-6 weeks, daily 4-hr sessions (total ± 120 hrs)	+			Multidisciplinary work re-entry rehabilitation program including physical conditioning, work conditioning/ simulation, job related pain and stress management and ergonomic consultation.
Ipsen et al. 2012	N=297; Chronic condition/ disability	Employment; Questionnaire.	? (not described)	No differences in employment rate between groups after 12 months	G	Trained Independent Living Center (ICL) staff	10 weeks, weekly 2-hr sessions (total 20 hrs)		+		Working well program, focusing on life values, goal setting, problem solving, pathway planning, healthy reactions, advocacy, stress management, physical activity, nutrition, and maintenance.
Haffey et al. 1991	N=199; Traumatic brain injury	RTW; Interview + questionnaire.	Usual care	Differences were not tested.I After 12 months 68% of IG and 34% of CG had paid employment (positive trend)		Vocational counsellor, job development specialist, vocational evaluator, job coach	3 months on average (total ± 60 hrs of staff assistance)			+	Work re-entry program, including vocational assessment, work hardening, job development, job analysis, job placement, transitional employment program, support and long-term follow-up.
Kendall & Thompson 1998	N=183; Chronic pain	Participation in productive activity; Questionnaire.	Waiting list	Differences were not tested.G After 15 months, 28.4% of IG and 9.8% of CG returned to work		Psychologist, occupational therapist, physiotherapist, nurse, medical registrar	6 weeks, 12 half-day sessions (total 48 hrs)		+		Cognitive-behavioural pain-management program, focusing on self-management and increased participation in productive activity, addressing pain management, problem solving, stress management

Table 2 Characteristics of the included studies and interventions (continued)

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS					
Study	Method				Delivery characteristics			Intervention content		
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
LI et al. 2006	N=64; Musculoskeletal injuries	Work readiness; C-Laser1	Waiting list	Significant improvement in work readiness in IG compared with CG after 3 wks (p< 0.05)	GI	Vocational counsellor, occupational therapist, social worker	3 weeks with daily group sessions 2-3 hrs, 3 individual sessions of 1 hr (total ± 40 hrs)		+		Training on work readiness using cognitive behavioural approach, addressing pain and stress management, decisional balance and self-efficacy, coping strategies, re-employment training.
LI-TSANG et al. 2008	N=63; Musculoskeletal injuries	RTW/Work readiness/ Work productivity; C-Laser1.	Usual care (advice on job placement)	IG showed higher RTW rate than CG (p=0.05) and significant differences in work readiness (p=0.05) after 3 wks. No differences in hours worked (WP) between groups	GI	Case-manager	3 weeks with 4 1-hr individual sessions + 5 group sessions (total ± 14 hrs)			+	Job Placement and Support Program, including role play, case-management, structured job searching and preparation.
MACEDO et al. 2009	N=32; Rheumatoid Arthritis	Work productivity; RA-WIS, Questionnaire	Usual care	RA WIS significantly improved in IG compared to CG at 6 months (p=0.04); no significant differences for work days missed (positive trend)	I	Occupational therapist specialized in RA and vocational rehabilitation	6 months, with 6-8 sessions of 0.5-2 hrs (total 3-16 hrs)			+	Comprehensive occupational therapy, including assessments (work, functional and psychosocial), ergonomic review; stress management; assertiveness, self-advocacy, activities of daily living, work visits.
MARHOLD et al. 2001	N=72; Chronic pain	Number of days on sick leave; Objective data from NIA	Usual care	No significant effect was found for the patients on long-term sick leave compared to CG, after 6 months	GI	Psychologist; access to physician, nurse, physiotherapist, occupational therapist	12 weeks, with weekly 2.5-hr sessions and 2 booster sessions (total 35 hrs)		+		Cognitive behavioural return-to-work program addressing pain coping, goal setting, graded activity, pacing of activities, relaxation, cognitive techniques, stress management, problem solving.

Table 2 Characteristics of the included studies and interventions (continued)

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS					
Study	Method				Delivery characteristics			Intervention content		
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
Marnetoft & Selander 2000	N=47; Musculoskeletal disorders	Level of benefit/ Sick days; Objective data from NIA	Usual care (multi-disciplinary program)	Significant more persons in IG than CG had lower level of benefits; no significant differences in sick days between IG and CG after 12 months	GI	Physician, physiotherapist, occupational therapist, rehabilitation counsellor, nurse, case manager, supervisor work training	8-17 weeks; 4 wks daily 6-hrs sessions, followed by 4-13 wks individual work training (total >120 hrs)			+	Extended multidisciplinary vocational rehabilitation program, including work training with case management addressing identifying problems, strengthen resources and self-confidence.
MARTIN et al. 2012	N=174; HIV/AIDS	Employment activities; Structured interview	Single session offering community referrals	Mean summed scores of IG and CG did not differ after 12 months. Mean scores of IG were higher at follow-up (24 months) than CG (p=0.03) (positive trend)	GI	Psychologist, vocational counsellor, HIV positive peer	7 weeks; 13 2-hr sessions + 3 1-hr individual sessions (total 29 hrs)			+	Mixed (group–individual) modality intervention that incorporated elements of motivational Interviewing, skills building, job-related skills.
MEYER et al. 2005	N=33; Chronic pain	Work ability; Work status (%); Assessment by physician	Treatment according to recom-mendations for 8 wks by a physician	No significant differences between IG and CG after 32 weeks	GI	Rehabilitation physician, psychologist, social worker, occupational therapist, physio-therapist, case manager	8 wks, daily sessions 3.5 hrs (5/wk) (total 140 hrs)			+	Work rehabilitation programme using an operant behavioural therapy approach, including education in ergonomics, learning strategies to cope with pain and to increase self-efficacy, workplace visit.
Niemeijer et al. 2010	N=71; Acquired brain injury	Work status; Employability; Employability Rating Scale	Waiting list	No differences in employment rate between IG and CG after 6 months (p = 0.41) or in employability (p = 0.13)	G	Trained staff of 6 clubhouses for community dwelling persons with ABI	10 weeks, 20 sessions (total ± 20 hrs)		+		Vocational Transitions Program, addressing overcoming obstacles, goal-setting, strategies for improving memory for work and daily living, self-awareness, stress management, problem-solving.

Table 2 Characteristics of the included studies and interventions (continued)

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS					
Study	Method				Delivery characteristics			Intervention content		
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
OTTOMANELLI et al. 2012	N=201; Spinal Cord Injury	Competitive employment; Interviews and chart distraction	Usual care	Employment rate was significantly greater for IG than for CG (p=.003) after 12 months; persons in IG worked significantly more hrs/wk (p=.000)	I	VR counselor (integrated into interdisciplinary SCI treatment team)	SE services were provided during 1 year (mean 36 hrs)			+	Spinal Cord Injury Vocational Integration Program, based on Supported Employment, including integrated vocational and medical rehabilitation, job finding, competitive employment, ongoing job support, focus on participant preferences.
SALAZAR et al. 2000	N=120; Traumatic brain injury	RTW and fitness for military duty; Interview and military records.	Home rehabilitation	No significant difference between patients from IG vs CG in return to employment (90% vs 94%; P=.51) after 12 months	GI	Physiatrist, neuro-psychologist, speech pathologist, occupational therapist, rehabilitation assistant	8 weeks, daily program (group and individual therapies) (total ± 160 hrs).			+	Intensive, standardized, 8-week in-hospital cognitive rehabilitation program. Group therapies addressed planning and organization, cognitive skills, pragmatic speech, psychotherapy and community reentry. Placement in various (military) work settings.
Schlademann et al. 2007	N=129; Rheumatoid Arthritis	Sick leave; Questionnaire	Usual care	No significant differences between IG and CG in sick leave after 12 months	I	Multidisciplinary team; professionals not described	3 weeks, in-patient+ rehabilitation				Counselling on medical rehabilitation, 3-weeks in-patient program.
SKOUEN et al. 2006	N=215; Chronic pain	RTW (no of days absence); Objective data from NIA	Usual care	Differences between IG and CG for total group not described; women attending extensive program showed significantly fewer sick days (p=0.02) after 12 months (positive trend)	GI	Physician, psychologist, physiotherapist, nurse	4 weeks, 6-hr daily+ program (5 days/ wk) (total 120 hrs)				Extensive multidisciplinary treatment, addressing cognitive coping strategies, body awareness training, occasional workplace intervention, lifestyle.

Table 2 Characteristics of the included studies and interventions (continued)

STUDY CHARACTERISTICS					INTERVENTION CHARACTERISTICS					
Study	Method				Delivery characteristics			Intervention content		
	Participants (n, diagnosis)	Outcome and measurement	Control	Results	Ta	Professionals	Duration/ frequency	P	CB	V	Program description
STÖRRO et al. 2004	N=218; Chronic pain	Work status; Objective data from NIA	Usual care	There was a significant difference in proportion taken off the sick list after 12 months p< 0.001)	G	Physician, physiotherapist, psychologist	4 wks, 3 2-hr sessions per wk (total 24 hrs)	+			Active multidisciplinary treatment. Developing insight into the process of pain perception, self-confidence, reduction of fear-avoidance behaviour, and greater skills to cope with pain.
Sullivan et al. 2006	N=130; Chronic pain	RTW; Interview	Physical therapy	After 4 weeks significantly more participants in IG (75%) than CG (50%) had returned to work (p<.01)	I	Physical therapist, occupational therapist	Maximum of 10 weeks, weekly 1-hr sessions (total 10 hrs)	+			Progressive Goal Attainment Program (PGAP) using cognitive techniques and physical therapy, maximizing activity involvement through activity monitoring, activity prescription, and graded activity participation.
Varekamp et al. 2011	N=122; Chronic physical disease	Job maintenance/ self-efficacy in at work; Questionnaires	Usual care	No differences in job maintenance between IG and CG. Self-efficacy increased significantly more in IG than CG (p=0.000) after 24 months (not tested after 12 months)	GI	Group trainer with psychotherapeutic knowledge, occupational physician, employment expert, actor (role play)	20 weeks, 7 3-h group sessions + 3 individual sessions (total 24 hrs)		+		Job maintenance training program focusing on work related problems from an empowerment perspective: aiming to enhance the knowledge, self-awareness and skills in order to help participants solve problems at work.

Abbreviations: T=Treatment, P=Physical focus; CB=Cognitive-Behavioural Focus; V=Vocational Focus; IG=Intervention Group; CG=Control Group; NIA= National Insurance Authority.

[a] Treatment (T) is divided in: Group (G), Individual (I) or combination (GI). High-quality studies are indicated in capital letters.

(32-34, 36, 37, 47, 49-51, 54). All interventions targeting cognitive-behavioural functioning included group treatment.

Effectiveness of interventions on work participation and quality of the evidence

Overall, ten studies showed significant improvement of work participation (31, 34, 35, 39, 42, 46, 47, 53-55), another six studies suggested a positive trend (33, 36, 37, 45, 49, 52) and nine studies showed no effect (32, 38, 40, 41, 43, 44, 48, 50, 51). Characteristics and effectiveness of interventions are summarized in Table 3. Twenty studies addressed one of the three specified outcome measures, four studies addressed two outcomes and one study addressed all three outcomes. Below we describe the effects and the quality of evidence for each of the three outcomes, i.e. work status, work productivity and work attitude. These results are summarised in Table 4 and Figures 2-4.

Effects on work status

Twenty studies measured changes in work status, e.g. return to work, employment, job maintenance (Figure 2). Overall characteristics of the interventions addressing work status varied widely, but a majority included group treatment (13 interventions, 65%) and used a multidisciplinary approach (12 interventions, 60%); most were characterised by a vocational (n=8) or physical focus (n=7) (Table 3).

These 20 studies showed heterogeneous effects on work status: eight studies showed statistically significant ($p<0.05$) improvement after the intervention (31, 34, 35, 39, 42, 47, 53, 54); four studies showed a positive trend (36, 37, 45, 52) and eight studies found no effect on work status (32, 38, 41, 43, 44, 50, 51, 55). Due to limitations in study design, inconsistency of results and imprecision, the quality of the body of evidence for this outcome is very low (see Table 4).

Effects on work productivity

Five (HQ) studies measured changes in work productivity (Figure 3). Common characteristics of these interventions were a monodisciplinary approach and the absence of a physical focus (Table 3). In addition, most interventions included group treatment as well as a long duration with low frequency (60%).

Two studies showed statistically significant ($p<0.05$) improvement of work productivity after the intervention (34, 39), one showed a positive trend (33) and two showed no effect (47, 48) (Figure 3). Due to inconsistency and imprecision, the quality of the body of evidence for this outcome is low (Table 4).

Table 3 Characteristics and effectiveness of the interventions

		Outcome[a]			Effect			Studies		
	Number of studies	Work status	Work productivity	Work attiude	Number of studies with significant effect (HQ)[b] (n=10)	Number of studies with positive trend (HQ)[b] (n=6)	Number of studies with lack of effect (HQ)[b] (n=11)	With significant effect	With positive trend	With lack of effect
Treatment										
• Individual	**8**	7	2	-	**3 (1)**	**3 (2)**	**2 (1)**	(31, 34, 35)	(33, 36, 37)	(32, 38)
• Group/combined	**17**	13	3	6	**7 (4)**	**3 (3)**	**9 (4)**	(39, 42, 46, 47, 53-55)	(45, 49, 52)	(40, 41, 43, 44, 47, 48, 50, 51, 55)
Professionals										
• Monodisciplinary	**11**	8	5	3	**4 (3)**	**3 (3)**	**5 (2)**	(31, 34, 39, 47)	(33, 37, 45)	(40, 41, 44, 47, 48)
• Multidisciplinary	**14**	12	-	3	**6 (3)**	**3 (2)**	**6 (3)**	(35, 42, 46, 53-55)	(36, 49, 52)	(32, 38, 43, 50, 51, 55)
Duration & frequency										
• Short High	**9**	7	1	3	**5 (3)**	**2 (2)**	**3 (-)**	(31, 42, 46, 47, 53)	(49, 52)	(38, 43, 47)
Low	**1**	-	-	1	**-**	**-**	**1 (-)**			(40)
• Moderate High	**3**	3	-	1	**-**	**-**	**3 (2)**			(44, 50, 51)
Low	**4**	3	1	-	**1 (-)**	**-**	**2 (1)**	(35)		(32, 41)
• Long High	**2**	2	-	-	**1 (-)**	**1 (-)**	**-**	(54)	(36)	
Low	**6**	5	3	1	**3 (2)**	**3 (3)**	**2 (1)**	(34, 39, 55)	(33, 37, 45)	(48, 55)
Focus of program										
Physical	**7**	7	-	-	**4 (1)**	**2 (2)**	**1 (-)**	(31, 35, 42, 53)	(45, 52)	(38)
Cognitive-behavioural	**8**	5	2	4	**3 (2)**	**-**	**6 (1)**	(39, 46, 55)		(40, 41, 43, 44, 48, 55)
Vocational	**10**	8	3	2	**3 (2)**	**4 (3)**	**4 (4)**	(34, 47, 54)	(33, 36, 37, 49)	(32, 47, 50, 51)
Diagnosis					*MSD (5x), Pain (3x), SCI, Various*	*Pain (2x), RA (2x), HIV, TBI*	*MSD, Pain (3x), RA (2x), TBI (2x) Various (3x)*			

Abbreviations: MSD: Musculoskeletal Disorder; RA: Rheumatoid Arthritis or rheumatic diseases; Pain: chronic pain; Various: population of various chronic physical diseases; TBI: Traumatic Brain Injury, SCI: Spinal Cord Injury; HIV: Human Immunodeficiency Virus;
(HQ): number of high-quality studies (from the total number of studies) with significant effect, positive trend, lack of effect.
[a]: Total number of studies based on effectiveness on one of three outcomes: n=31 (work status: n=20, work productivity: n=5, work attitude: n=6)
[b]: Studies that show different (effective and not effective) results on different outcomes are included in both categories, resulting in n=27 outcomes from 25 studies.

Table 4 Evidence profile for the outcomes work status, work productivity, work attitude

	Quality assessment					Number of patients		Quality of the evidence
Number of studies (design)	**Limitation in design**	**Inconsistency**	**Indirectness**	**Imprecision**	**Publication bias**	**I[a]**	**C[b]**	
Work status 20 studies (13 RCT, 7 CCT)	Ten studies show limitation in design or follow-up.	Heterogeneity: 8 studies (4 HQ) showed significant improvement, 4 studies (3 HQ) showed a positive trend and 8 studies(3 HQ) showed no effect.	No serious indirectness; the control condition is usual care in most studies.	Total sample size is large: 2321 patients. The 95% CIs include no effect for half of the studies.	Possible publication bias, indicated by asymmetric funnel plot. Studies were not funded by industry	1165	1156	Very low
	Decision: Moderate quality of evidence	Decision: Rating down for inconsistency	Decision: No serious indirectness	Decision: Rating down for imprecision	Decision: Not rating down for publication bias			
Of which: *Diagnosis: Chronic Pain* *(7 studies)*	*High quality evidence*	*No serious Inconsistency*	*No serious indirectness*	*Rating down for imprecision*	*Publication bias unlikely*	377	414	Moder-ate
Diagnosis: MSD *(4 studies)*	*Moderate quality evidence*	*No serious inconsistency*	*No serious indirectness*	*Rating down for imprecision*	*Publication bias unlikely*	119	116	Low
Work productivity 5 studies (RCT)	No serious limitation in design. Information is from studies at low risk of bias.	Heterogeneity: 2 HQ studies showed significant improvement, 1 HQ study showed a positive trend, 2 HQ studies showed no effect.	No serious indirectness: in 4 studies the control condition is usual care, in 1 study waiting list.	Total number of patients included is 219. CIs of all studies include no effect.	Possible publication bias because lack of large trials. Studies were not funded by industry	117	102	Low
	Decision: High-quality evidence	Decision: Rating down for inconsistency	Decision: No serious indirectness	Decision: Rating down for imprecision	Decision: Not rating down for publication bias			
Work attitude 6 studies (5 RCT, 1 CCT)	Three studies show limitation in design.	Heterogeneity: 3 studies (2 HQ) showed significant improvement, 1 HQ study showed a positive trend, 2 studies showed no effect.	No serious indirectness: in 5 studies the control condition is usual care, in 1 study waiting list.	Total number of patients included is 521. The 95% CIs include no effect for 3 out of 5 studies.	Possible publication bias because lack of large trials. Studies were not funded by industry	270	251	Very low
	Decision: Moderate quality evidence	Decision: Rating down for inconsistency	Decision: No serious indirectness	Decision: Rating down for imprecision	Decision: Not rating down for publication bias			

[a] I=Intervention: number of patients who received the intervention studied.

[b] C=Control: number of patients who received the control condition (usual care or no care).

Effects on work attitude

Six studies measured changes in work attitude (Figure 4). One study could not be included in the forest plot because standard deviations (SD) of scores were unknown, therefore mean differences could not be calculated (49). Common characteristics of these interventions were group treatment and the absence of a physical focus (Table 3). In addition, most interventions were characterised by a short duration as well as a cognitive-behavioural focus (67%).

Three studies showed statistically significant ($p<0.05$) improvement of work attitude after the intervention (46, 47, 55), one study showed a positive trend (49) and two studies reported no effect (40, 44). Due to limitations in study design, inconsistency and imprecision, the quality of the body of evidence for this outcome is very low (Table 4).

Overall, the results with regard to effectiveness support both group and individual treatment, a multidisciplinary and monodisciplinary approach, a short duration (with high frequency) and a long duration (with low frequency), and a physical as well as a vocational focus of interventions. However, we found no support for a cognitive-behavioural focus and a moderate duration of interventions because most interventions with these characteristics lacked effect with regard to work participation.

For specific chronic conditions, we found moderate quality evidence for effectiveness in chronic pain and low quality evidence for effectiveness in musculoskeletal disorders (MSD) (Table 4, Figure 2). The analyses did not reveal specific characteristics of effective interventions, although most interventions for persons with chronic pain and for musculoskeletal disorders applied group treatment (88% and 80%, respectively) and used a multidisciplinary approach (63% and 60%, respectively). Results for persons with spinal cord injury (SCI) were positive but based on one study. Results varied for the other diagnoses, i.e. rheumatic diseases (RA), traumatic brain injury (TBI), and populations with various chronic physical diseases. Interventions for persons with rheumatic diseases were characterised by individual treatment (most with a low frequency); interventions for persons with various other chronic physical diseases had in common: group treatment, a cognitive-behavioural focus and a low frequency.

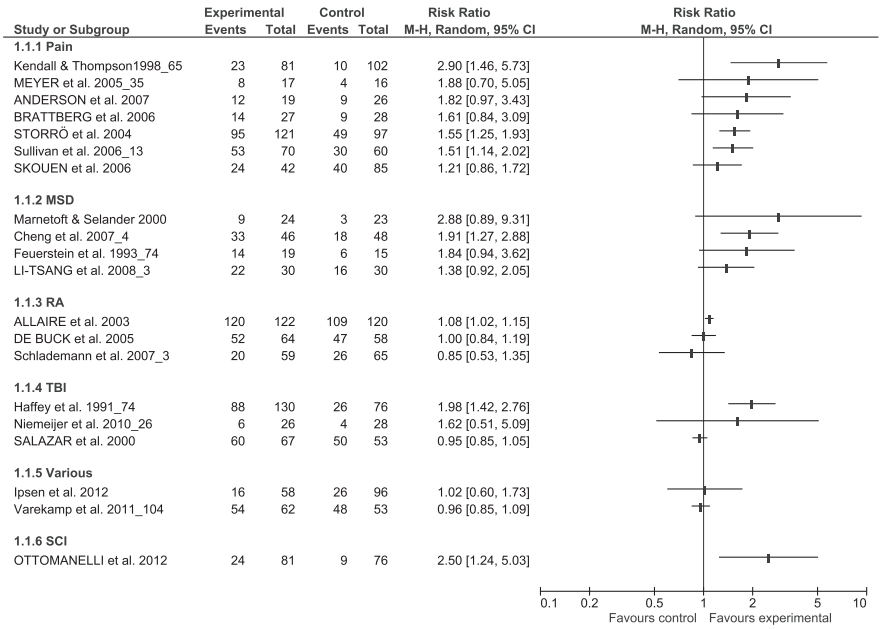

Figure 2 Forest plot of effectiveness of interventions on outcome: work status
Abbreviations: Pain: chronic pain; MSD: Musculoskeletal disorders; RA: Rheumatoid arthritis or rheumatic diseases; TBI: Traumatic brain injury, Various: study population with various chronic physical diseases; SCI: Spinal cord injury. High-quality studies are indicated in capital letters.

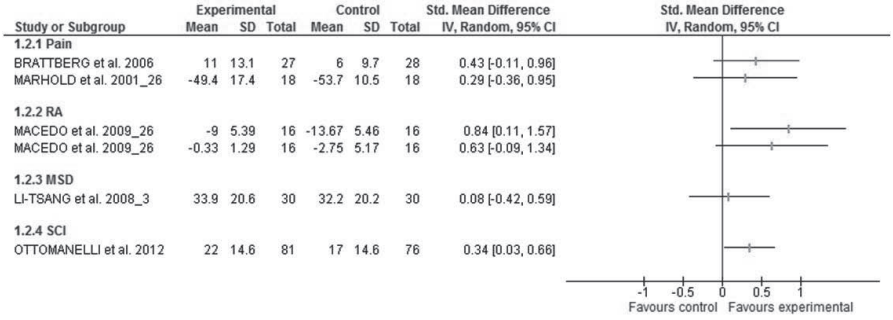

Figure 3 Forest plot of effectiveness of interventions on outcome: work productivity
Abbreviations: Pain: chronic pain. RA: Rheumatoid arthritis or rheumatic disease; MSD: Musculoskeletal disorders; SCI: Spinal cord injury. High-quality studies are indicated in capital letters.

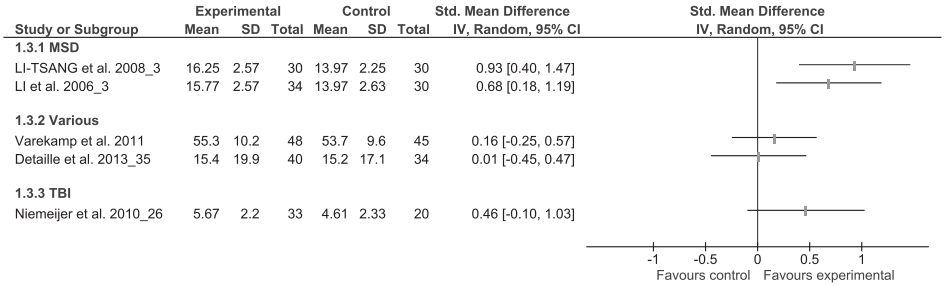

Figure 4 Forest plot of effectiveness of interventions on outcome: work attitude
Abbreviations: MSD: Musculoskeletal disorders; Various: study population with various chronic physical diseases; TBI: Traumatic brain injury. High-quality studies are indicated in capital letters.

DISCUSSION

This systematic review investigated characteristics and effectiveness of interventions aiming to improve work participation in adults with various chronic physical conditions of at least 3 months duration, excluding back disorders. The results of 25 controlled studies provide some evidence for effectiveness of interventions aiming to improve work participation, although interventions varied widely regarding delivery characteristics and content. Interventions including group treatment, a multidisciplinary approach and a high frequency (mostly lasting < 8 weeks) were most frequently applied. However, interventions with these characteristics were equally applied in studies with and without positive effect.

Overall, the direction of the effect seems to be positive and the results provided evidence for effectiveness of interventions aiming to improve work participation. Considering the three outcomes of work participation, we found very low quality evidence for effectiveness of interventions on work status and work attitude, and low quality evidence for work productivity. More specifically, we found somewhat better quality evidence for effectiveness of interventions on work status in patients with chronic pain or musculoskeletal disorders.

The large variation in content and effects of interventions addressing work participation might be explained by the broad scope of the present review, and is consistent with other systematic reviews addressing return to work interventions in broad populations with various chronic disorders (15, 56). A stronger evidence base on effectiveness of vocational interventions for musculoskeletal disorders, and more evidence for cost benefits, was reported in (explorative) studies reviewing the scientific evidence for vocational rehabilitation in the UK and the Netherlands (57, 58). Notwithstanding the wide variation in interventions aiming to improve work participation of persons with various chronic conditions, they

also shared generic components that enabled categorisation, such as individual or group treatment, and mono- or multidisciplinary approach.

We found inconsistent evidence for effectiveness of a multidisciplinary approach on improved work participation. These findings are similar to a systematic review in persons with low back pain (16), but not in agreement with two other systematic reviews finding evidence for effectiveness of multidisciplinary interventions on return to work, addressing persons with (physical and mental) chronic conditions on sick leave and persons with chronic low back pain (56, 59). The positive results of interventions applying monodisciplinary treatment we presented must be considered with some caution, because two out of four effective monodisciplinary interventions were provided by a vocational specialist after patients had participated in a rehabilitation program, or in collaboration with a multidisciplinary team (34, 47). In addition, structured multidisciplinary interventions might be more intense and difficult to provide, presenting a higher risk of bias due to follow-up periods that are too short to reveal the effects or, with a longer follow-up period, a risk of non-compliance or loss to follow-up. This may increase the chance of non-significant results and can lead to publication bias, since studies with positive findings are more likely to be published.

Regarding duration and frequency of interventions, all high quality studies with significant positive effects were characterised by either a short duration and high frequency or a long duration and low frequency, while interventions with a moderate duration (8-12 weeks) showed a lack of effect. However, comparing these results with other reviews is difficult due to the different classifications used.

The finding that interventions with an emphasis on physical functioning appeared to be effective is consistent with the results of other systematic reviews addressing employees with chronic back pain (17, 18). In interpreting these findings, it should be remembered that the present review only included interventions that contained specific elements to improve work participation. These interventions, although focusing on physical functioning, often also included other elements, such as education, behavioural strategies or ergonomic consultation. The effects of these combined strategies cannot be disentangled. In addition, almost all (6 of 7) interventions with a physical focus addressed patients with chronic pain or musculoskeletal disorders, who might be more amenable to physical recovery and improved physical functioning over time, in contrast to irreversible conditions (e.g. SCI).

We found no support for interventions focusing on a cognitive-behavioural approach, which is in line with a review addressing chronic back pain (18). The lack of effect of these interventions might be because most interventions applied a group program without providing additional individual treatment (63%), while

persons with a chronic condition often face complex situations and may benefit from individual and ongoing support, especially for problems in the cognitive-behavioural domain. Furthermore, the achievement of behavioural change may be more difficult to realise (60).

We found inconsistent evidence for interventions with an emphasis on vocational functioning, because four high quality studies showed a lack of effect. In this review, only three interventions focusing on vocational functioning involved structured communication with the employer (31, 33, 47); two of these studies showed positive effects and the other showed a positive trend. These findings are similar to other reviews reporting that workplace-based interventions are effective in supporting return to work, especially when stakeholders, including the employer, are in close collaboration (17, 61). Therefore, inclusion of this component in interventions might be recommended.

Finally, our results indicate that interventions showing positive effects on work participation do not share common characteristics that can be indicated as effective elements. This suggests that the focus on work participation that is applied in a specific context, might be more important than the specific elements included in the intervention. The finding that interventions with varying characteristics seemed to be more effective in patients with chronic pain or musculoskeletal disorders, might be due to explained the higher expectations of physical recovery in these conditions over time, which can be improved by an intervention.

Strengths and limitations of the review

We provided a broad overview on the effectiveness of interventions aiming to improve work participation in patients with various chronic conditions, in contrast to most previous reviews that focused on a specific diagnosis. Application of the GRADE method to evaluate the quality of the evidence for the outcomes work status, work productivity and work attitude increased the reliability and validity.

Some limitations need addressing, related to the review itself as well as to the underlying evidence base. The literature search may not have been complete because we did not include observational studies or search for grey literature. In case of missing information in publications, the corresponding author of the original paper was not contacted for missing data. The generally positive findings in a non-specific way may be explained by bias, because there were few large trials included and an asymmetric funnel plot indicated possible publication bias.

Main limitations of the included studies involved lack of standardised outcome measures, the small sample sizes, and the different follow-up periods. Due to heterogeneity in outcome measures, we were unable to perform a quantitative meta-analysis. Eleven studies had ≤ 35 participants in each intervention arm and

might have lacked power to detect intervention effects. Not all studies included a follow-up period up to 12 months; in addition, in some studies outcomes at 12-month follow-up were not reported and could not be ascertained (e.g. from related studies). Therefore, we had to use the outcome at another follow-up moment as a proxy and explicitly reported this in our overview; however, this could have biased our results. For the outcomes work productivity and work attitude, only a limited number of studies were available. Combined with heterogeneity and imprecision of results, this contributed to the qualification of low or very low quality of evidence for these outcomes.

Finally, the comparison of return to work rates of interventions originating from different countries should be considered with caution, since differences in social security policies will affect rates of sick leave and return to work (62).

Implications for practice and research

Although a generic conclusion on effective (elements of) interventions to improve work participation of persons with a chronic condition experiencing work disability cannot be presented, the overview of interventions in this review enables healthcare professionals to address work participation within rehabilitation. Main implications for clinical practice are twofold. First, addressing work participation within the rehabilitation of persons with a chronic condition using systematic and targeted interventions, including vocational issues (e.g. job demands, work environment, work ability, work limitations) seems beneficial to improve or sustain work participation, regardless of the specific intervention characteristics and diagnosis. Second, the large variation in effective interventions shows that interventions aiming to improve work participation of persons with a chronic condition might be composed of various potential effective components based on a multidimensional perspective, addressing physical, emotional, social and environmental aspects of work participation within the intervention. Inclusion of communication and collaboration with the employer, although incorporated in only a few interventions, showed positive effects.

This systematic review revealed a need for further research on interventions aiming to improve and sustain work participation in persons with a chronic physical condition. Future research should focus on high quality RCTs and include large sample sizes in order to detect intervention effects and improve the quality of evidence. To increase the consistency of the evidence, similar or comparable outcome measures for work participation across studies should be used. To decrease risk of bias and improve quality of the evidence, studies should include a follow-up period long enough (≥ 12 months) to evaluate outcomes of work participation. Primary outcome measures should be assessed and reported on

all follow-up measurements; in addition, outcome measures and measurement instruments should, preferably, be comparable or standardised across studies. Furthermore, interventions should be adequately described to enable comparability of intervention components and application in practice. A 12-item template for intervention description and replication (TIDieR) checklist has been published to facilitate better reporting of interventions (63).

Especially for chronic conditions other than chronic pain or musculoskeletal disorders (e.g. RA, TBI, SCI) further research is needed to determine effective interventions to improve work participation.

CONCLUSION

Our results from 25 controlled studies provide evidence for interventions aiming to improve work participation in persons with a chronic physical condition. Interventions varied widely regarding content and delivery characteristics; although interventions including group treatment and a multidisciplinary approach were used most frequently, they did not show more effectiveness than individual and monodisciplinary interventions.

We found low quality evidence for effectiveness with regard to work productivity, and very low quality evidence for effectiveness with regard to work status and work attitude. The quality of the evidence was better for effectiveness with regard to work status in patients with chronic pain and musculoskeletal disorders.

The finding that effective interventions did not share common characteristics may suggest that addressing work participation within the rehabilitation of persons with a chronic condition, using systematic and targeted interventions, seems beneficial to improve or sustain work participation, regardless of the specific intervention and diagnosis.

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Chapter 3

Development of work participation in young adults with cerebral palsy: a longitudinal study

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ABSTRACT

Objective: To document the development of work participation in young adults with cerebral palsy who are transitioning into adulthood, examine associated characteristics, and investigate work limitations and barriers among employed persons.

Design: Observational longitudinal cohort study.

Subjects: Seventy-four young adults with cerebral palsy of average intelligence, aged 16-20 years at baseline.

Methods: Work participation in 3 categories (employed, unemployed, studying) was assessed at baseline, 2-year and 4-year follow-ups using structured interviews. At 4-year follow-up, associations of work participation with demographic and clinical characteristics were examined using multinomial logistic regression. Work limitations and barriers among employed persons were evaluated using questionnaires.

Results: From age range 16-20 years to age range 20-24 years the proportions of subjects who were employed and unemployed increased from 12% to 49% and 3% to 17%, respectively; the proportion who were students decreased from 85% to 34%. In the age range 20-24 years, the employment rate of young adults with cerebral palsy was lower and the unemployment rate higher, than that of the general population. A lower level of gross motor function and younger age were associated with unemployment. Employed persons experienced few work limitations; 28% experienced situational or health barriers.

Conclusion: Young adults with cerebral palsy and average intelligence are at risk of experiencing unfavorable developments in work participation. Rehabilitation services should offer support to prevent unemployment and occupational disability.

Cerebral palsy (CP) is the leading cause of physical disability in childhood, affecting movement and posture and leading to activity limitations and participation restrictions. CP is a chronic condition, and dramatic increases in life expectancy have increased awareness about the need to support persons with CP throughout their life course. During the process of transition to adulthood young people have to develop a range of new skills needed for assuming adult roles and for becoming independent, autonomous adults who manage their own lives (1-6). The transition process involves different domains of participation, e.g. independent living, social/community life, education and employment. For young adults, work participation is important for providing financial independence, but also for social interaction and a sense of self-esteem. Studies among young adults with CP found that (part-time) paid work is among the 3 most frequently identified problems, and that they consider problems in work to be very important (5, 7, 8).

Many adults with CP experience participation restrictions in different areas of life, including employment (1, 2, 9-11). Estimated employment rates for adults with CP vary widely. These variations might be due to the different age groups studied, differences in clinical characteristics, the inclusion of part-time or sheltered employment in some studies, and the influence of different social systems between countries. For the USA and Sweden reported employment rates for adults with CP (age range 17-74 years) are approximately 50% (2, 11-13); for Canada employment rates of 50% and 36% are reported for adults aged 20-33 years (14, 15). For European countries (including Denmark, Italy, England), Australia and Israel reported employment rates for adults with CP (age range 16-65 years) are between 34% and 38% (1, 16-19); for Taiwan an employment rate of 23% is reported for adults with CP aged 18-54 years (20). In the Netherlands, rates of paid employment of 54% are reported for a broad sample of adults with CP aged 25-36 years (n=54, 48% male), including persons with intellectual disabilities (3), and of 68% for adults aged 25-45 years (n=56, 62% male) with bilateral spastic CP of average intelligence (9). In both studies, the majority had a high level of gross motor function (62% and 73% scored Gross Motor Functioning Classification System (GMFCS) levels I-II) and completed some form of secondary education (54% and 73%).

In general, favourable factors for employment among young people with various (physical or mental) disabilities are male gender, older age, higher educational level, higher level of intelligence, higher psychosocial level of functioning, low depression scores, ambulation or transportation independence, self-care independence and having a disability for a long time; while intellectual disability (intelligence quotient (IQ) ≤ 80), more severe physical disability, epilepsy and dependent or denial coping strategies are unfavourable factors for employment

(14, 21-24). For persons with CP, lower levels of gross motor function, bilateral CP, intellectual disability, epilepsy, lower levels of general self-efficacy, dependence in daily activities, and assisted living are unfavourable factors for employment and social participation (8, 9, 16, 19, 20).

Previous studies have not systematically examined the development of work participation in young adults with CP during their transition to adulthood prospectively over some years, or examined the work limitations and barriers to employment that they experience.

Therefore, we prospectively followed a sample of Dutch young adults with CP of average intelligence, who were in the age range 16-20 years, for a period of 4 years up to the age range of 20-24 years. The primary aim of this study was to document the longitudinal development of work participation in young adults with CP during their transition to adulthood over a 4-year period. A further aim was to examine the associations of demographic and clinical characteristics with work participation in young adults with CP who were in the age range 20-24 years. Finally, we aimed to determine experienced work limitations and situational or health barriers to employment among employed persons.

METHODS

Participants

This observational study was conducted as part of the CP transition study in the South-West Netherlands, in which a cohort of young adults in the age range 16 to 20 years was followed over a period of 4 years in order to study their process of transition to adulthood in several areas of life (4).

Participants were recruited from 8 rehabilitation centres and rehabilitation departments in the south-western region of the Netherlands. Participants did not receive rehabilitation interventions to improve their transition to adulthood.

Inclusion criteria were 1) a diagnosis of CP, 2) aged 16 - 20 years at baseline, and 3) average intelligence (corresponding with an estimated IQ ≥ 70). Persons with an additional diagnosis with persisting effects on motor functioning and persons with inadequate proficiency with the Dutch language were excluded.

Measurements were performed at baseline in 2002 (n=103), at 2-year follow-up (n=87) and at 4–year follow-up (n=78). The current study focuses on work participation and presents the results of 74 participants for whom data on education and employment were available at all three assessments. No significant non-response or loss-to-follow-up biases were observed with respect to age, gender, gross motor functioning, and laterality of CP. At 2-year and 4-year follow-

up, however, there were fewer participants with a low education level (27% and 23%), compared with baseline (39%, p=0.02) (5, 25).

All participants gave verbal and written informed consent. The Medical Ethics Committee of Erasmus University Medical Center Rotterdam approved the study.

Measurements

Data were collected by means of physical examination, structured interviews and standardized questionnaires administered in the presence of a researcher. Demographic and clinical data, as well as work participation were measured at baseline, 2-year follow-up and 4-year follow-up. At 4-year follow-up additional measurements were performed for work limitations and perceived situational or health barriers in employed persons.

Sample characteristics

The following characteristics were recorded: age, gender, type and laterality of CP, gross motor function, manual ability, level of education, general self-efficacy and parents' level of education.

Type (spastic/non-spastic) and laterality of CP (unilateral/bilateral) were established in accordance with guidelines of the Surveillance of Cerebral Palsy in Europe (SCPE) (26).

Gross motor function was classified according to the Gross Motor Functioning Classification System (GMFCS), a 5-level classification system for CP based on spontaneous movement with an emphasis on sitting and walking (27).

Manual ability was classified with the Manual Ability Classification System (MACS), a 5-level system that classifies manual performance of children with CP (28, 29). Both classifications have shown to be valid for use with young adults with CP (29). Higher levels of GMFCS and MACS indicate better functioning.

Level of education of participants was categorized as High: secondary general education, higher professional education or university (International Standard Classification of Education (ISCED) levels 3 (general), 6 or higher), Medium: pre-vocational theoretical education or upper secondary vocational education (ISCED levels 3 (vocational), 4 or 5), and Low: pre-vocational practical education or lower (ISCED levels 1 or 2) (4, 30).

General self-efficacy was assessed with the Dutch language version of the General Self-Efficacy Scale-12 (GSES-12) (31). The 12 items are scored on a 5-point Likert scale. Total scores, and scores for subscales Initiative, Effort and Persistence were calculated. Scales have demonstrated satisfactory levels of internal consistency and test-retest reliability (31). Higher scores indicate a more positive perceived self-efficacy.

Work participation

Work participation was assessed using structured interviews addressing work participation, employment situation (type of job, work hours) and occupational disability. We distinguished 3 categories of work participation: 1) employed, including paid and unpaid employment; 2) unemployed and (3) studying.

We defined employed as performing (paid or unpaid) work for ≥ 12 h/week; unpaid employment was included in this category because it is important for young adults for entering the labour market and for social participation (32). The lower bound of 12 h a week was based on the labour force definition used by Statistics Netherlands (33), thus allowing comparison of data of the study sample with the general Dutch population. Studying was defined as being engaged in secondary or tertiary education as part of the formal education system (34). Participants were classified in 1 of 3 categories according to their main activity.

Work limitations and perceived situational or health barriers

In employed persons work limitations were assessed at 4-year follow-up using the modified Dutch-language version of the Work Limitations Questionnaire (WLQ-mdlv), a reliable and valid self-report instrument (35, 36). Scores on the 25 items are organized in 4 scales addressing specific job demands: Time Management (5 items), Physical Demands (6 items), Mental-Interpersonal Demands (9 items), and Output Demands (5 items). Scale scores can be interpreted as the percentage of time in the previous 2 weeks that a person was limited in performing specific job demands. The WLQ index is calculated from the 4 scales; higher scores indicate more work limitations.

Perceived situational or health barriers to employment (yes/no) among employed persons were assessed at 4-year follow-up, using a 28-item questionnaire from the national Amenities and Services Utilization Survey (AVO) of the Netherlands Institute for Social Research (37). The questionnaire comprised 9 items addressing situational barriers (e.g., work pace, work hours, work tasks, adequate facilities), 8 items addressing health problems (e.g., pain, fatigue, mobility, absence) and 11 items addressing work adjustments (e.g., adjusted work hours, work tasks, facilities, support of colleagues).

Statistical analyses

Descriptive statistics were used to present demographic and clinical characteristics, work participation, work limitations, and perceived situational or health barriers.

To assess the development in work participation, we analysed differences in proportions employed, unemployed and students at baseline, 2-year follow-up

compared with 4-year follow-up, using Cochran's Q and McNemar's test. Cochran Q was used for testing overall differences over time; *post-hoc* McNemar test was used to compare paired proportions at 2 different assessments (0-2; 2-4; 0-4 years). Binomial tests (1-sided) were applied for comparison of proportions of employed, unemployed and students in the study sample with reference values of the general Dutch population in the age range 20-25 years in the year 2006 that were obtained from the electronic databank of Statistics Netherlands (StatLine) (33).

To assess associations of demographic and clinical characteristics with work participation at 4-year follow-up we conducted (cross-sectional) multinomial logistic regression analyses. Multinomial regression was used because the outcome variable had 3 values (employed, unemployed, study). Selection of independent variables studied was based on the literature, addressing age, gender, laterality of CP, level of education, gross motor function, manual ability, self-efficacy and parental level of education (9, 16, 21, 22, 38). Independent variables were dichotomized (high level of education vs low and medium level of education of participants and parents; GMFCS levels I-II vs levels III-V; MACS level I vs levels II-V). Scores on GSES were dichotomized at the median scores of the study sample identifying high (including the median) and low levels of general self-efficacy.

We used a 2-step approach to limit the number of independent variables to be included in a model, accommodating for the small sample size. First, univariate models were tested for one independent variable at a time. Secondly, multivariable analysis was performed entering the statistical significant ($p<0.05$) independent variables of the first step into the model in order to examine the unique contribution of each of these independent variables to the prediction of work participation.

The WLQ-mdlv was completed by 31 of the 36 persons employed at 4-year follow-up, meaning missing data for 14% of the subsample on the WLQ-mdlv. One-sample t-tests were applied for comparison of WLQ-mdlv scores with reference values of healthy employees (35).

Analyses were performed using SPSS 19.0 statistical software. For all analyses, a significance-level of 0.05 and 95% confidence level was used.

RESULTS

Characteristics of the study sample (n=74) and subgroups of employed, unemployed and students are shown in Table I. Almost all participants had a spastic paresis (96%), almost half of them were classified as unilateral CP (47%), the

Table I Characteristics of the study population at 4-year follow-up

	Study sample (n=74)	Employed (n=36)	Unemployed (n=13)	Student (n=25)
Age, years, mean (SD)	22.8 (1.4)	23.4 (1.4)	21.8 (1.1)	22.6 (1.3)
Male gender, n (%)	45 (61)	23 (64)	6 (46)	16 (64)
Laterality of CP, n (%)				
Unilateral	35 (47)	17 (47)	3 (23)	15 (60)
Bilateral (diplegia/tetraplegia)	23/16 (53)	14/5 (53)	3/7 (77)	6/4 (40)
GMFCS level, n (%)				
I	54 (73)	28 (78)	6 (46)	20 (80)
II	7 (9)	5 (14)	2 (15)	0 (0)
III-V	13 (18)	3 (8)	5 (39)	5 (20)
MACS level, n (%)				
I	60 (82)	31 (86)	8 (62)	21 (87)
II	9 (12)	4 (11)	2 (15)	3 (13)
III-V	4 (6)	1 (3)	3 (23)	0 (0)
Level of education, n (%)				
High	27 (36)	10 (28)	3 (23)	14 (56)
Medium	30 (41)	16 (44)	3 (23)	11 (44)
Low	17 (23)	10 (28)	7 (54)	0
General Self-efficacy, mean (SD)				
Total	45.5 (5.7)	46.3 (5.5)	44.1 (8.0)	44.9 (4.8)
Effort	14.9 (3.6)	15.3 (3.2)	13.7 (5.4)	14.9 (3.2)
Persistence	20.9 (2.9)	21.3 (2.8)	21.0 (4.0)	20.2 (2.4)
Initiative	11.3 (2.8)	11.5 (2.7)	9.9 (3.5)	11.4 (2.4)
Parents' level of education[a], n (%)				
High	25 (35)	9 (24)	4 (33)	12 (48)
Medium	37 (52)	17 (50)	8 (67)	12 (48)
Low	9 (13)	8 (26)	0	1 (4)

Due to missing values: MACS level, n=73; GSES, n=71; parents' level of education, n=71.

[a] Measured at baseline.

GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; SD: standard deviation.

others as bilateral CP (53%). The majority (73%) had a high level of gross motor functioning, indicating no limitations in ambulation, and a high level of manual ability. Seventy-seven percent followed secondary theoretical or higher education.

Work participation

Development of work participation from baseline to 2-year and 4-year follow-up is shown in Figure 1. The proportion of employed persons (including paid and unpaid employment) increased from baseline to 2-year follow-up (12% vs 26%, p=0.004) and from 2-year to 4-year follow-up (26% vs 49%; p<0.001). The proportion of unemployed persons increased from baseline to 2-year follow-up (3% vs 14%, p=0.04), stabilizing between 2- and 4-year follow-up (14% vs 17%). The proportion of students decreased from baseline to 2-year follow-up (85% vs 60%, p=0.001) and from 2-year to 4-year follow-up (60% vs 34%, p<0.001).

In addition, a total of 16 participants (22%) reported established occupational disability, i.e. (partial) occupational disability pension is granted, at baseline (n=4), 2-year follow-up (n=9) or 4-year follow-up (n=8). Five persons reported established occupational disability at 2 measurements; none of the participants reported established occupational disability at all 3 measurements. Some par-

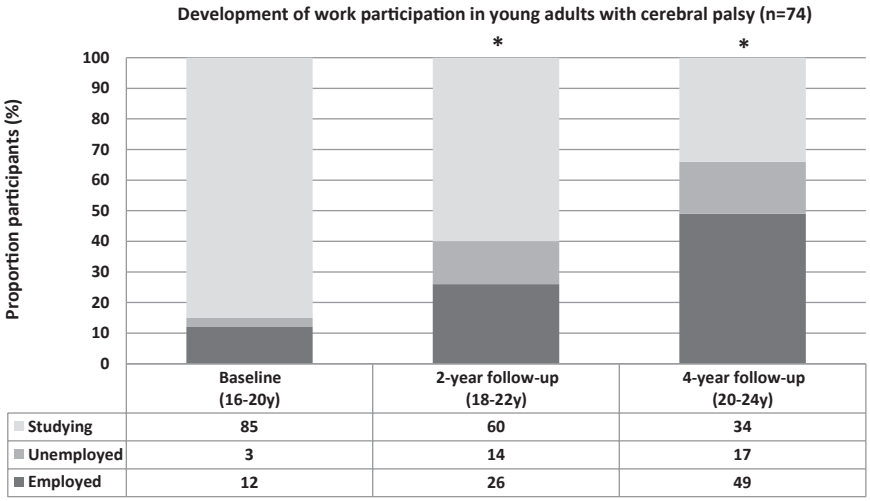

Figure 1 Development of work participation in young adults with cerebral palsy (n=74)
Employed includes both paid and unpaid employment; unpaid employment: baseline n=1 (1%), 2-year follow-up n= 4 (5%), 4-year follow-up n= 2 (3%). * Indicating significant differences in proportion employed participants.

ticipants with established occupational disability were (gainfully) employed or students.

At 4-year follow-up, in the age range 20- 24 years (mean age 22.8 yr), a total of 36 (49%) young adults with CP were employed (see Fig. 1). Of these, 34 (46%) had paid employment, of whom 29 (39%) were in competitive and 5 (7%) in sheltered employment. Two persons (3%) had unpaid employment. Eighteen out of 19 persons who were employed at 2-year follow-up, were still employed at 4-year follow-up, showing that they were able to maintain employment.

On average, employed persons worked 32.8 h/week (standard deviation (SD) 9.3). Most of them (72%; n=26) worked 32 h/week or more, with 10 persons working ≥ 40 h. Four persons were working 24-31 h/week, and six persons 12-23 h/week. Employed persons performed a broad variety of jobs in 10 of the 13 categories identified in the Dutch Standard Occupational Classification (39). Eighty percent of employed persons performed a job that was consistent with their level of education: 21% had a job requiring a high level of education, 44% a medium level and 35% a low level of education.

Thirteen persons (17%) were unemployed at 4-year follow-up; 7 of them were looking for a job, 6 others reported established occupational disability and received a disability pension. Longitudinal trajectories of those unemployed persons show that at 2-year follow-up, 4 persons were unemployed, 1 person was employed and 8 persons were studying; at baseline 1 (other) person was employed and 12 persons were studying. Four persons were unemployed both at 2-year and at 4-year follow-up; 3 of them reported established occupational disability at both measurements.

One third of the study sample were studying (n=25) at 4-year follow-up.

Table II Work participation of young adults with cerebral palsy (CP) aged 20-24 years compared with the general population

	Study sample at 4-year follow-up (20-24 years) % (n)	Reference group: general population (20-25 years) %
Employed[a]	49 (36)	59*
Unemployed	17 (13)	8**
Student	34 (25)	44*

*p<0.05; **p<0.01

[a] Persons with unpaid employment (n=2) were included.

Note that the percentages of employed, unemployed and students in the general population add up to more than 100%, probably because persons may combine education with part-time employment.

At 4-year follow-up, the employment rate in young adults with CP (49%; including two persons with unpaid employment) was lower than in the general Dutch population in the age range 20-25 years (59% in 2006; $p<0.05$), and the proportion of unemployed persons was higher (17% versus 8%; $p<0.01$) (33). Also, the proportion of students was lower than in the general population at this age (34% versus 44%; $p<0.05$) (Table II).

Factors associated with work participation

At 4-year follow-up employed persons did not differ from unemployed persons and students in gender, laterality of CP, manual ability, self-efficacy and parents' level of education (Table III). Three variables (age, gross motor function, and level of education) were significantly associated with work participation in the univariate analyses. In the multivariable analysis these variables remained statistically significant, showing that each made a unique contribution to the prediction of 1 of 3 categories of work participation. The adjusted odds ratios show that participants with a lower age were more likely to be unemployed or studying than employed. Participants with a lower level of gross motor function were more likely to be unemployed than employed; participants with a higher level of education were more likely to be studying than employed. The logistic model including age, GMFCS level and level of education correctly classified 66.2% of cases in three categories, and 77.8% of employed persons, 46.2% of unemployed and 60.0% of studying.

Experienced work limitations and situational or health barriers among employed persons

At 4-year follow-up, WLQ-mdlv scores of employed persons indicate that they were limited on the job approximately 10% of the time in the previous 2 weeks, especially in physical and output demands (Table IV). They had significantly more work limitations in physical demands compared with reference values of healthy employees (mean score 4.5 (SD 1.4)) (1-sample t-test, $t=2.12$, $p<0.05$) (35, 40). Reported difficulties in physical demands concerned lifting, carrying or moving objects, and sitting or standing in one position for some time while working. Moreover, items of the physical demands scale were often scored as 'Does not apply to my job (DNA)'. In total, 27 items (3.5%) were scored as DNA, of which 17 on the physical demands scale (9.1% of responses of the scale).

A majority of the employed persons (72%) perceived no situational or health barriers to employment; 3 of them (8%) had work adjustments. Ten persons (28%) reported 1 or more situational or health barriers interfering with their work, notwithstanding the use of 1 to 5 work adjustments in 5 of them. These

Table III Demographic and clinical characteristics of participants associated with work participation (employed, unemployed, student) at 4-year follow-up

		UNIVARIATE MODELS[a] Reference category: employed				MULTIVARIABLE MODEL[a] Reference category: employed			
		Unemployed		Student		Unemployed		Student	
		OR	95% CI	OR	95% CI	aOR	95% CI	aOR	95% CI
Independent variables									
Age		**0.38****	0.21-0.70	**0.57***	0.37-0.92	**0.30*****	0.15-0.62	**0.45****	0.26-0.77
GMFCS level	High (I-II)	**0.15***	0.02-0.74	0.36	0.07-1.68	**0.08****	0.01-0.52	0.23	0.04-1.25
	Low (III-V)								
Level of education	High	0.78	0.18-3.43	**3.31***	1.12-9.70	2.23	0.38-13.24	**6.31****	1.70-23.32
	Low								
Gender	Male	0.48	0.13-1.75	1.01	0.35-2.90				
	Female								
Laterality of CP	Unilateral	0.34	0.08-1.43	1.67	0.60-4.71				
	Bilateral								
MACS level	High (I)	0.36	0.08-1.64	1.13	0.24-5.24				
	Low (II-V)								
Self-efficacy	High	0.63	0.16-2.44	0.81	0.29-2.28				
(GSES)	Low								
Parents' level of education	High	1.38	0.34-5.76	2.56	0.86-7.65				
	Low								

*p<0.05; **p<0.01 ***p<0.001

[a]Multinomial logistic regression analysis; Outcome variable: work participation, in 3 categories (employed, unemployed, student).

OR: odds ratio; aOR: adjusted OR; CI: confidence interval; GMFCS: Gross Motor Function Classification System; MACS: Manual Ability Classification System; GSES: General Self Efficacy Scale.

Table IV Work limitations of employed persons with cerebral palsy at 4-year follow-up as measured with the Work Limitations Questionnaire (WLQ) (n=31)[a]

	Employed persons (n=31)[a]	Employed; no situational or health barriers (n=23)	Employed; ≥ 1 situational or health barriers (n=8)
	mean (SD)	mean (SD)	mean (SD)
Time management	9.2 (14.0)	5.9 (9.7)	18.8 (20.1)
Physical demands	10.8 (16.4)	5.4 (10.0)	25.7 (21.7)*
Mental-Interpersonal demands	9.6 (12.1)	7.6 (11.4)	15.3 (13.1)
Output demands	12.9 (17.8)	9.1 (11.0)	23.8 (27.1)
WLQ index	3.0 (3.7)	2.0 (2.5)	5.8 (5.1)

*p<0.05;significant differences between employed persons experiencing no barriers and persons experiencing ≥ 1 barriers.
[a] 5 employed persons did not complete the WLQ; 2 of them experienced situational or health barriers.
SD: standard deviation.

persons reported more work limitations on all WLQ-mdlv scales and showed significantly higher scores (meaning more limitations) on the physical demands scale compared with those not experiencing situational or health barriers (Mann-Whitney U test: p=0.018; Z=-2.55) (Table IV). Situational barriers addressed work hours (n=2), work pace, work tasks (unsuited), or other (transport, attitude colleagues). Health barriers that were reported were fatigue (n=5), pain (n=2), absence, concentration, mental problems or other (fine motor skills, lifting objects).

Eight employed persons (22%) had work adjustments, concerning work hours (n=2), work pace (n=2), work tasks, adequate facilities (n=4) or other (lift, transport, job coach, assistance, education); 3 of them reported no situational or health barriers.

DISCUSSION

Work participation

To our knowledge, this is the first cohort study to document the longitudinal development of work participation in a sample of young adults with CP of average intelligence during their transition to adulthood. This study adds to our knowledge on the transition to employment in young adults with CP, showing that approximately 50% of them are employed at the age of 20-24 years, furthermore indicating that 1 in 4 employed persons with CP experiences situational or health

barriers in performing their job. In addition, this study demonstrates that young adults with CP are at an increased risk for unemployment.

In the age range 20-24 years a significantly higher proportion of young adults with CP was employed compared with 2 and 4 years earlier, working on average approximately 33 h per week. Young adults with CP who achieved employment seemed able to maintain employment over several years. Both the increasing proportion of employed persons and the decreasing proportion of students over the 4-year period might be expected from an age-appropriate developmental process that is in accordance with the transition to adulthood (8). We expect the employment rate of the study sample to further increase when they become older and grow into adulthood, since one-third was still studying at the age of 20-24 years. Reduced employment rates in young adults with CP under the age of 26 years and age as important factor for employment outcomes were previously reported by Bottos et al. and Huang et al. (13, 18). However, the increasing proportion of persons with CP that are unemployed over time, as well as the relatively high proportion of persons in young adulthood that are unemployed indicate that a significant part of the sample was at risk for an unfavourable development in work participation.

At 4-year follow-up, approximately half of the unemployed persons reported established occupational disability; on the other hand some persons with established occupational disability achieved paid employment and did not need to receive (partly) disability pension. In the Netherlands young adults with established occupational disability (of 25% or more at their 17th birthday) are entitled to disability pension from their 18th birthday. Although for young adults with a chronic condition established occupational disability might be permanent, the amount of disability pension may vary. Some young adults with established occupational disability might continue studying because of lack of employment opportunities.

In addition, this study shows the discrepancy in employment outcomes for young adults with CP compared with Dutch age-mates. The employment rate of young adults with CP found in this study is in line with, or compares favourably with, other studies in CP (2, 11, 12, 16-19) and is in line with the 47% employment rate reported for people with disabilities in the Netherlands in 2006 (37). We found support for the importance of lower gross motor function with regard to unemployment, in addition to younger age (16, 18, 21-23). In contrast, those factors that are potentially amenable to interventions seemed not to be associated with work participation (such as manual ability, general self-efficacy); depression or coping strategies were not studied in this sample.

Work limitations and perceived situational or health barriers

Those young adults with CP who were employed experienced few work limitations. We might assume that they tend to perform jobs that are not physically demanding, since items of the work limitations questionnaire addressing physical demands were most often scored as 'Does not apply to my job'.

Most of the employed persons perceived no situational or health barriers and did not use work adjustments. However, approximately 25% of them did experience situational or health barriers to employment. The latter persons showed higher scores on the WLQ-mdlv scales, indicating that the WLQ can be a useful instrument for revealing work problems among employed young adults with CP. The barriers they reported, such as work hours, fatigue or pain, might be amenable to interventions.

Study limitations

Generalization of our results is limited to young adults with CP of average intelligence with relatively high levels of gross motor function and manual ability. Due to the small sample size the results should be interpreted with some caution, as indicated by large confidence intervals regarding associated factors for work participation and a small number of employed persons that reported work limitations on the WLQ. In addition, due to the differential drop-out of persons with a low level of education at follow-up, results on work participation over time might be slightly biased, with a possible over-estimation of the proportion students at follow-up. Since work participation may be influenced by legislation and the labour market within countries, and by socio-economic factors, such as insurance and social services, some caution is needed when generalizing the results of this study to other countries.

A longer follow-up period, until age 25-30 years, might be needed to provide more information about work participation at adult age, since over 30% of the sample is still studying.

Notwithstanding these limitations, the present study provides important insights into the transition to employment in a well-documented sample of young adults with CP, indicating that young adults with CP with high levels of gross motor function and of average intelligence show a relatively high unemployment rate.

Implications for clinical practice

The finding that relatively low proportions of young adults with CP and average intelligence were employed or studying, and a relatively high proportion was unemployed, compared with the general population of the same age, indicates that

young adults with CP might need support to prevent unemployment. Due to their young age, they have much to gain in achieving employment during many years. Besides providing financial independence, work experience in young adults can contribute to discovering and developing personal interests and skills, but also to increased awareness of physical abilities and limitations (41, 42).

Interventions should focus on preventing the risk of unemployment among young adults with CP, by evaluating and training work ability and providing support in finding suitable employment. Providing support shortly after completing formal education might be most effective since early intervention and prevention are key issues in vocational rehabilitation (41). Based on our findings, special attention should be paid to young adults with CP with a lower level of gross motor function, since they are expected to encounter more challenges in achieving suitable employment.

Secondly, approximately 25% of the employed persons with CP experienced situational or health barriers in performing their job. They may profit from interventions aiming to prevent occupational disability by decreasing barriers and evaluating work adjustments. Vocational rehabilitation interventions may support these young adults and encourage vocational planning as part of lifespan care. Young adult teams, using a multidimensional and multidisciplinary approach, are specialized in supporting the transition to adulthood in several domains of participation, including employment. They offer programs aiming to support young adults to develop necessary life skills and to adapt to changing roles in adult life (4, 5, 43, 44). Young adults with CP might profit from a vocational rehabilitation intervention provided by young adult teams to improve work participation in suitable employment, and to prevent occupational disability and unemployment (43).

In conclusion, this study shows that young adults with CP and average intelligence are at risk for an unfavourable development in work participation, showing a lower employment rate (49% vs 59%) and a higher unemployment rate (17% vs 8%) in the age range 20-24 years compared with the general Dutch population of the same age. One out of 4 employed persons experienced situational or health barriers to employment, mainly fatigue or pain; work limitations addressed mainly output and physical demands.

Rehabilitation services might offer support to prevent unemployment and occupational disability, focusing on younger persons with CP and lower levels of gross motor function who are at increased risk for unemployment and on employed young adults with CP who experience work limitations.

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Chapter 4

Using the work limitations questionnaire in patients with a chronic condition in the Netherlands

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ABSTRACT

Objective: to examine the intelligibility and psychometric properties of the modified Dutch language version of the Work Limitations Questionnaire (WLQ) (WLQ-mdlv).

Methods: Employed patients with a physical chronic condition completed the WLQ-mdlv, the Work Ability Index and the 36-item Short-Form Health Survey (SF-36). Intelligibility, internal consistency, test-retest reliability and external construct validity of the WLQ-mdlv were assessed.

Results: In 125 patients, the WLQ-mdlv showed improved intelligibility for a Dutch population. With Cronbach α coefficients more than .80, squared weighted κ of 0.63 or more (individual items), intraclass correlation coefficients of 0.83 or more (WLQ scales), a minimal detectable change of four points (WLQ-index), and negative correlations with the Work Ability Index and related Short-Form Health Survey scales reliability and external construct validity of the WLQ-mdlv were confirmed.

Conclusion: The WLQ-mdlv is an intelligible, reliable and valid instrument for evaluating work limitations in employees with a chronic condition in the Netherlands.

Employees with a chronic health condition often have work-related problems resulting in sick leave, job loss, unemployment, or early retirement. To prevent long-term absenteeism or job loss, they may have to adjust working hours and type of work or forego a promotion (1-3).

In many European countries, rates of work disability are increasing (4). Among working adults in the USA, 32% reported to have a chronic condition that interferes with their job performance (1). In the Netherlands 37% of employees have a chronic disease or handicap, hampering the work performance of almost half of them (5). Increasing numbers of employees with a chronic condition within the aging labor force, together with social policy aiming at job retention for individuals with a chronic condition, require usable, reliable and valid assessments to identify work ability and work limitations and to monitor response to treatment aimed at decreasing work disability (6).

The Work Limitations Questionnaire (WLQ) is a self-administered 25-item questionnaire that is frequently used to measure the impact of chronic health conditions on job performance and work productivity among employed individuals (1, 2, 7-10). The WLQ has shown good reliability and construct validity among various patient populations, such as those with osteoarthritis, rheumatoid arthritis, chronic headache, and epilepsy (1, 2, 11). The test-retest reliability of the WLQ has not yet been assessed (10, 12).

The WLQ is available in English with more than 30 official language translations; a Dutch language version has been available since 2006 (13, 14). The translation of the Dutch language version of the WLQ-25 was performed by the MAPI Institute, an international company with expertise in the translation and linguistic validation of patient-reported and clinical assessments. The protocol for the translation process included forward translation by two native speakers who are experienced in translating health questionnaires, harmonization, backward translation, and testing on three to five patients. The Dutch language version of the WLQ-25 that we received from the authors (14) was, in fact, phrased in the Belgian Dutch language, with minor differences in phrasing compared with the official Dutch language. We slightly altered the phrasing according to the official Dutch language to produce the modified Dutch language version of the WLQ-25 (WLQ-mdlv), to be used in the Netherlands. This study aims to examine the intelligibility, reliability, and external construct validity of the WLQ-mdlv in employed adults with various chronic conditions.

METHODS

Prestudy

In a prestudy (n=33) the intelligibility of the WLQ-mdlv was assessed compared with the Belgian Dutch WLQ. Patients were assigned randomly to the Belgian Dutch version (n=16) or to the WLQ-mdlv (n=17). When completing the WLQ, participants were asked to mark WLQ questions they considered clear or easy to understand with a plus ('+'), and questions they considered vague or difficult to understand with a minus ('-').

After completing the WLQ, in a 5- to 10-minute interview, participants were asked to explain the plusses and minuses they scored, focusing on the minuses. In addition, they were asked three overall questions about the WLQ version they completed, addressing (1) their overall opinion about the WLQ, (2) the sentence structure of the questions and (3) the phrasing of the questions. To determine the intelligibility of the Belgian Dutch WLQ and the WLQ-mdlv, plusses and minuses for each item on both versions were counted, and comments from interviews were classified.

Mean age of the participants of the prestudy was 41.6 years (SD, 10.9); 63.6% were women. Self-reported diagnosis was classified using the International Classification of Diseases – *Tenth Revision* (ICD-10) (15) as diseases of the musculoskeletal system (n=24) (eg, back pain, knee injury, frozen shoulder, arthrosis, rheumatoid arthritis), neurological diseases (n=7) (eg, stroke, muscular disease, multiple sclerosis), diseases of the circulatory system (n=1), and unknown (n=1) .

Participants who completed the Belgian Dutch version criticized sentence structure (41%), phrasing or linguistic use of words (24%) and the length of the sentences (29%). Participants who completed the WLQ-mdlv only criticised the length of the sentences (24%).

The prestudy was performed as a first phase of the study. Because the results of the prestudy demonstrated that the WLQ-mdlv showed improved intelligibility for a Dutch population compared with the Belgian Dutch version, we decided to use the WLQ-mdlv to study its reliability and external construct validity.

Participants of the prestudy also completed the Work Ability Index (WAI) and 36-item Short-Form Health Survey (SF-36), and data of the 17 participants who completed the WLQ-mdlv were included in the larger study sample to study its internal consistency and external construct validity. Nevertheless, data of participants of the prestudy were not included in the analysis for test-retest reliability.

Study design

Employed patients with various chronic conditions were approached by research assistants in the waiting rooms in outpatient clinics of Erasmus MC University Medical Center (Orthopaedics, Rehabilitation Medicine), EmCare Center for occupational health services for employed persons with musculoskeletal disorders, Rijndam Rehabilitation Centre, and two practices for physical therapy in primary health care.

Inclusion criteria were: diagnosed with a chronic physical condition; employed and working 12 hours a week or more (16); and perceived interference of the chronic condition with job performance (in general). Patients who had insufficient comprehension of the Dutch language or cognitive or mental disorders hampering understanding the questionnaire were excluded.

All participants were informed about the research both verbally and in an information letter, and all signed an informed consent form. This study was part of a larger study on work participation. The Medical Ethics Committee of Erasmus MC Rotterdam approved the study.

Participants completed a questionnaire, including demographic characteristics (age, gender, chronic condition, education, employment), the WLQ-mdlv, WAI and the SF-36. Completion of the questionnaire required about 30 minutes. After they completed the WLQ, participants were asked to participate in a 5- to 10-minute interview about the intelligibility of the WLQ.

All participants received a numbered copy of the WLQ-mdlv and a stamped envelope, and were asked to return the completed questionnaire after 1 week. The retest period was chosen within the 2-week reporting period of the WLQ to aim at unchanged health conditions.

Measurements

The WLQ is a self-administered questionnaire measuring the impact of chronic conditions on job performance. Scores on the 25 items of the WLQ generate four scale scores: Time Management scale (TMS) (five items), Physical Demands scale (PDS) (six items), Mental-Interpersonal Demands scale (MIDS) (nine items) and Output Demands scale (ODS) (five items) (1, 2). Employees rate their work limitations in the previous 2 weeks on a five-point scale from 'None of the time' to 'All of the time', or 'Does not apply to my job'. Scores for items within each scale are summed, and the resulting sum is divided by the number of items within the scale. Resulting scale scores are transformed mathematically to 0 (Limited none of the time) to 100 (Limited all of the time). Missing items and items that were scored 'does not apply' were handled according to the WLQ-manual, meaning that scales were scored if half or more of the items had been answered with valid,

nonmissing responses (17). Responses to WLQ scales are used to generate a WLQ index that can range from 0 to 28 and that can be interpreted as an estimated percent of productivity loss (17, 18). Higher scores on the WLQ index indicate more work limitations.

The WAI is a self-administered questionnaire that reveals how well a worker can perform his work (19). The overall WAI score is calculated by summation of the 7 item scores and can range from 7 to 49 points. On the basis of the WAI score, an individual's work ability can be classified into four categories: poor (7 to 27 points), moderate (28 to 36 points), good (37 to 43 points), and excellent (44 to 49 points). Higher scores indicate better work ability. The WAI is a reliable and valid standardized measure of work ability (20, 21).

The SF-36 aims to measure health-related quality of life with 36 questions, organized into 8 multi-item scales: physical functioning (PF), role limitation due to physical health problems (RP), bodily pain, general health perception, vitality, social functioning (SF), role limitation due to emotional problems (RE), and general mental health (22). In addition, scores are summarized in a physical component summary (PCS) and a mental component summary (MCS) (23, 24). Scale and summery scores are converted to a scale of 0 to 100, with higher scores indicating better health-related quality of life. The Dutch language version of the SF-36 is reliable and valid for use in chronic disease populations (25).

Intelligibility

Intelligibility of the WLQ-mdlv was assessed using the plus-minus method, a reader-focused method for text evaluation (26). The plus-minus method and the accompanying interview were described in the prestudy section. For items that were rated with a minus by 10% of participants or more, explanatory comments from interviews were used to suggest improvements.

Reliability

Reliability of the WLQ-mdlv was tested initially by internal consistency that was assessed by Cronbach α coefficient. We examined WLQ scale scores for floor and ceiling effects, defining small floor or ceiling effects (1 to 15% of the sample achieving the minimum or maximum scores) as meeting standards (27).

In addition, test-retest reliability and measurement error of the WLQ-mdlv were determined using two procedures:

1. For individual WLQ items, we used the squared weighted κ (SWK) for agreement. The SWK is used for ordinal measures and takes into account the amount of disagreement between two measurements (28, 29).

2. For WLQ scales and index, the intraclass correlation coefficient (ICC), standard error of measurement (SEM), and associated minimal detectable change (MDC) at the 95% confidence level were calculated, also indicated as smallest detectable difference (28, 30, 31). The ICC, using a two-way random-effects model (subject by session) and the absolute agreement definition ($ICC_{2,1}$), is the preferred method to quantify reproducibility taking into account systematic variability (28, 29, 31). Test-retest reliability was considered excellent when values of SWK or ICC exceeded 0.75, good for values from 0.60 to 0.74, moderate for values from 0.40 to 0.59, and poor for values below 0.40 (32).

The SEM includes both random and systematic components of measurement error, expressed in the metric unit of the measurement instrument (29). The SEM can be converted into the MDC, which is an indicator of sensitivity to change. Only differences between two consecutive measurements that exceed the MDC can be interpreted with 95% certainty as a real change, above measurement error, in individual measurement. We expressed MDC as a percentage of the total possible range of the measurement instrument to obtain a relative value and considered an MDC% smaller than 15 as an acceptable sensitivity to change because it can distinguish seven steps in the total measurement range (29).

External construct validity

External construct validity of the WLQ-mdlv was assessed through convergent validity with the WAI score and the SF-36 PCS, MCS, and scale scores for social, physical and role functioning. Because the WLQ measures limitations and the WAI and SF-36 measure ability and functioning, we expected negative correlations with other measures.

We hypothesized that the WLQ-mdlv index score, which is interpreted as productivity loss, will show a strong (≥0.60) negative correlation with the WAI score, which is interpreted as work ability.

We hypothesized moderate negative correlations ($0.40<r<0.60$) between the WLQ-mdlv index and the SF-36 component summary scores (PCS and MCS), representing limitations in social and role activities related to physical and mental health.

In addition, we hypothesized moderate negative correlations ($0.40<r<0.60$) between the WLQ-mdlv scales for TMS, MIDS, and ODS and the SF-36 scales RP, RE and SF, measuring problems with work and social functioning. Finally, we hypothesized a moderate negative correlation between the WLQ-mdlv PDS and SF-36 PF.

Statistical analysis

All descriptive data are presented as mean and SD, or percentage when appropriate.

Calculation of scale and index scores for the WLQ, WAI and SF-36 was performed according to the manuals (17, 19, 23, 24). We checked that WLQ scales and SF-36 scales were normally distributed.

To determine the intelligibility of the WLQ-mdlv, plusses and minuses for each item were counted, and comments from interviews were classified.

To examine reliability, we used SWK for individual WLQ items.

For WLQ scales and index, the ICC, SEM, and associated MDC at a 95% confidence level were calculated using the following formulas (28-30, 33):

ICC = variance between subjects (i.e., variance of interest)/ total variance (composed of variance between subjects and error variance), expressed as a ratio between 0 and 1

SEM = √ (error variance)

MDC = 1,96*√2*SEM.

To study external construct validity, Pearson correlation coefficients were used for associations between instruments.

All analyses were performed using SPSS 16.0 (IBM Inc, Chicago, IL). All tests were considered statistically significant if $P < 0.05$.

RESULTS

A total of 125 employed patients with various chronic conditions participated in the study and completed the WLQ; 97 persons in the study sample (77.6%) also completed the WAI and SF-36. Of those participants, 88 persons (70.4%) returned a completed copy of the WLQ after one week.

Mean age of the patients was 41.9 years (SD, 10.4; range 18 to 61 years), and 62% were women. Diagnoses were patient reported and were classified by the researchers using the *International Classification of Diseases – Tenth Revision* (15). Most participants (68%) suffered from a chronic disease of the musculoskeletal system, reporting complaints of the shoulder, elbow, wrist, knee, or hip (n=25), chronic back pain (n=15) or fibromyalgia (n=12), and rheumatoid arthritis, arthrosis, neck and upper extremity complaints, and scleroderma. Diseases of the nervous system included stroke, multiple sclerosis, muscular diseases, and spinal cord injury. Interviews demonstrated that some participants did not experience current work limitations but experienced work limitations in the past (Table 1).

Table 1 Characteristics of study participants (n=125)

	N
Age, yrs (mean, SD)	41.9 (10.4)
Male/Female (n, %)	47/78 (38/62)
Type chronic disorder (*International Classification of Diseases*)[1]	
Diseases of the musculoskeletal system and connective tissue	85
Diseases of the nervous system	21
Diseases of the digestive system	4
Endocrine, nutritional and metabolic diseases	3
Diseases of the circulatory system	3
Diseases of the respiratory system	3
Multiple diseases	5
Education[2]	
High (bachelor or master degree)	35
Medium (prevocational theoretical education)	52
Low (prevocational practical education or no education)	25
Employment[3], hr/week	
Fulltime (36-40)	30
24-35	34
12-23	38
Work ability, points	
Poor (7-27)	50
Moderate (28-36)	43
Good (37-43)	4
Work ability index (mean, SD)[4]	27.4 (5.5)
SF-36 values (mean, SD)[4]	
Physical component summery	35.4 (10.9)
Mental component summery	51.7 (10.9)
Physical functioning	57.6 (27.0)
Role limitation due to physical problems	41.6 (42.2)
Bodily Pain	52.8 (24.7)
General health perception	51.1 (22.9)
Energy Vitality	52.9 (21.3)
Social Functioning	64.6 (25.4)
Role limitation due to emotional problems	79.6 (37.3)
Mental Health	74.2 (17.4)

[1] n=124; n=1 missing
[2] n=112; n=13 missing
[3] n=102; n=23 unknown but >12 hrs /week
[4] n=97

Missing values analysis

A missing values analysis of WLQ scores for the total sample (n=125) showed that 4.1% of responses were missing, of which 3.2% were scored as 'Does not apply to my job'. Items of the Physical Demands scale (PDS) were the most scored as 'Does not apply' (11.6%); especially the item 'Lift objects'. Apart from items scored 'Does not apply', 30 WLQ items were missing (0.9%).

Table 2 Test-retest reliability of WLQ-mdlv items (n=88)

Item	Scale	Test Mean (SD)	Retest Mean (SD)	Difference test-retest Mean (SD)	SWK	DNA %
Work the required number of hours	TM	2.8 (1.1)	2.7 (1.2)	0.09 (0.67)	0.84	0
Get going at beginning of work day	TM	3.0 (1.4)	2.9 (1.3)	0.03 (0.70)	0.86	0
Start job on arrival	TM	2.3 (1.2)	2.4 (1.1)	-0.10 (0.63)	0.84	1.1
Work without breaks or rests	TM	3.4 (1.3)	3.1 (1.3)	0.28 (0.82)	0.78	2.3
Stick to routine or schedule	TM	2.6 (1.2)	2.3 (1.1)	0.24 (0.94)	0.66	3.4
Walk or move around	PD	2.2 (1.2)	2.3 (1.3)	-0.10 (1.05)	0.65	12.5
Lift, carry, move objects (> 10 lbs)	PD	2.9 (1.5)	2.9 (1.4)	0.08 (0.95)	0.78	28.4
Sit or stand more than 15 minutes	PD	2.6 (1.2)	2.7 (1.3)	-0.09 (0.75)	0.82	6.8
Repeat same motions	PD	2.8 (1.2)	2.9 (1.2)	-0.10 (0.80)	0.76	12.5
Bend, twist or reach	PD	2.7 (1.2)	2.7 (1.1)	-0.01 (1.01)	0.63	4.5
Use hand tools or equipment	PD	2.5 (1.3)	2.4 (1.3)	0.08 (0.92)	0.74	4.5
Keep mind on work	MID	2.4 (1.1)	2.3 (1.1)	0.06 (0.61)	0.85	0
Think clearly	MID	2.2 (1.0)	2.1 (1.0)	0.11 (0.69)	0.76	0
Work carefully	MID	2.1 (0.9)	2.0 (0.9)	0.15 (0.64)	0.75	1.1
Concentrate on work	MID	2.5 (1.1)	2.3 (1.1)	0.16 (0.66)	0.80	0
Work without losing train of thoughts	MID	2.4 (1.1)	2.4 (1.1)	-0.01 (0.79)	0.74	1.1
Read or use your eyes	MID	2.0 (1.1)	2.0 (1.1)	0.00 (0.75)	0.78	1.1
Speak with people	MID	1.7 (0.8)	1.6 (0.9)	0.04 (0.60)	0.75	3.4
Control temper around people	MID	1.8 (1.0)	1.8 (1.0)	-0.08 (0.63)	0.80	1.1
Help others to get work done	MID	2.0 (1.0)	2.2 (1.2)	-0.13 (0.74)	0.76	6.8
Handle workload	OD	2.7 (1.1)	2.7 (1.2)	0.07 (0.64)	0.84	0
Work fast enough	OD	2.7 (1.2)	2.6 (1.2)	0.09 (0.81)	0.76	0
Finish work on time	OD	2.5 (1.1)	2.4 (1.1)	0.11 (0.74)	0.77	5.7
Work without mistakes	OD	2.1 (0.9)	2.2 (1.0)	-0.03 (0.67)	0.75	1.1
Done what you are capable of	OD	2.4 (1.2)	2.4 (1.3)	0.07 (0.85)	0.77	1.1

DNA, does not apply (based on test-scores)
MID, Mental-Interpersonal Demands scale; OD, Output Demands scale; PD, Physical Demands scale; SWK: squared weighted ; TM, Time Management scale; WLQ-mdlv, modified Dutch language version of the Work Limitations Questionnaire.

The percentage of missing WLQ responses per item due to scoring 'Does not apply' are included in Table 2 for the subsample that participated in the test-retest analysis (n=88).

Missing items analysis for the WAI and SF-36 (n=97) showed that, for the WAI, 0.02% and for the SF-36, 0.01% of all answers were missing.

Intelligibility

The overall opinion of all participants (n=109) about the intelligibility of the WLQ-mdlv was that it was easy to understand and to answer.

Two of the 25 items were rated as unclear by 10% of the participants or more: item 5E: 'Feel that you have done what you are capable of' (17%); and item 2A 'Walk or move around' (11%).

Interviews revealed that the opposite direction of responses of the PDS was confusing for 10% of the participants. This, together with the example 'going to meetings' in item 2A, was reason for scoring most minuses. Some respondents reported inconsistency between text and grades in one answering possibility: in their opinion 'Some of the time' was less than 50% of the time. Some respondents expressed difficulties with the 2-week reporting period, because their health problems varied during the day or during the week *('If I answer this questionnaire on Monday I'm as fresh as a daisy, but if you ask me on Friday it's different').*

On the basis of the interviews, recommendation for future use of the WLQ-mdlv in the Netherlands is to change slightly the phrasing of item 5A of the ODS by removing the word 'feel'. For item 2A no changes are recommended because the comments refer to the question and not to the phrasing or translation.

Reliability

Internal consistency (n=125)

Cronbach α of the WLQ-mdlv scales ranged from 0.83 to 0.92 (Table 3). For all scales, Cronbach α does not increase if one of the items is deleted.

The Work Limitations Questionnaire scale scores did demonstrate small floor and ceiling effects, with values of 0.8% to 2.4% of the study sample achieving the minimum scale scores and 4.8% to 10.4% of the study sample achieving the maximum scale scores.

Test-retest reliability of the WLQ-mdlv (n=88)

Values of SWK for the WLQ-mdlv items are above 0.75 for 20 items, indicating excellent agreement, and between 0.63 and 0.75 for five items, indicating good agreement (Table 2).

Table 3 Internal consistency of WLQ-mdlv scales and index

WLQ Scale	Cronbach α
Time Management Demands	0.87
Physical Demands	0.83
Mental-Interpersonal Demands	0.92
Output Demands	0.87
WLQ index	0.80

WLQ-mdlv, modified Dutch language version of the Work Limitations Questionnaire.

Table 4 Test-retest reliability of WLQ-mdlv scales and index

WLQ Scale	Test Mean (SD)	Retest Mean (SD)	ICC (95%CI)	SEM	MDC	MDC%
Time Management Demands	44.8 (24.9)	42.0 (25.7)	0.91 (0.86-0.94)	7.8	21.7	22
Physical Demands	39.4 (24.1)	41.0 (24.6)	0.83 (0.74-0.88)	10.2	28.1	28
Mental-Interpersonal Demands	27.9 (19.6)	26.9 (21.2)	0.90 (0.85-0.94)	6.4	17.6	18
Output Demands	37.4 (22.1)	36.5 (24.6)	0.87 (0.80-0.91)	8.5	23.6	24
WLQ index	10.2 (5.3)	10.0 (5.8)	0.93 (0.89-0.95)	1.5	4.1	15

CI, confidence interval; ICC: intraclass correlation coefficient; MDC, minimal detectable change at 95% CI; MDC%, MDC expressed as percentage of the total possible range of the measurement scale; SEM, standard error of measurement; WLQ-mdlv, modified Dutch language version of the Work Limitations Questionnaire.

The ICCs of the WLQ scales are 0.83 or higher, which is excellent (29) (Table 4). The SEM ranges from 6.4 (MIDS) to 10.2 (PDS). The corresponding MDCs are 18 to 28 points, which is 18% to 28% of the measurement range, indicating that the WLQ-mdlv scales can distinguish four (PDS and ODS) to five steps (TMS and MIDS) on the total measurement range. The WLQ-mdlv index has a MDC value of four points, which is 15% of the measurement range, and shows acceptable sensitivity to change.

Further analysis showed that participants working fewer hours showed higher WLQ-mdlv index scores: the mean value of the WLQ-mdlv index was 8.4 (SD, 5.9) for participants working full time (n=23), 10.8 (SD, 5.0) for participants working 24 to 35 hours per week (n=25) and 12.9 (SD, 5.7) for participants working 12 to 23 hours per week (n=25).

External construct validity (n=97)

The WLQ-mdlv index score showed a strong negative correlation (-0.72) with the WAI score, thereby confirming the hypothesized association (Table 5). The

Table 5 Construct validity of WLQ-mdlv scales and index as compared to WAI and SF-36

	WAI Index	SF-36 PCS	SF-36 MCS	SF-36 PF	SF-36 SF	SF-36 RP	SF-36 RE
Time Management Demands	-0.73**	-0.55**	-0.46**	-0.43**	-0.63**	-0.53**	-0.46**
Physical Demands	-0.28**	-0.46**	-0.10	-0.36**	-0.17	-0.37**	-0.23*
Mental Interpersonal Demands	-0.64**	-0.37**	-0.63**	-0.30**	-0.67**	-0.51**	-0.51**
Output Demands	-0.65**	-0.48**	-0.49**	-0.38**	-0.65**	-0.58**	-0.45**
WLQ index	-0.72**	-0.53**	-0.55**	-0.42**	-0.69**	-0.61**	-0.52**

Values are Pearson correlation coefficients.
* Correlation is significant at the 0.05 level (2-tailed); ** Correlation is significant at the 0.01 level (2-tailed).
MCS, Mental Component Summery; PCS, Physical Component Summery; PF, Physical functioning; RE: Role limitation due to emotional problems; RP, Role limitation due to physical problems; SF, Social Functioning; SF-36, 36-item Short-Form Health Survey; WAI, Work Ability Index; WLQ-mdlv, modified Dutch language version of the Work Limitations Questionnaire.

moderate negative correlations between the WLQ-mdlv index score and SF-36 component summery scores (PCS, -0.53; MCS, -0.55) were consistent with the hypothesized associations.

The WLQ-mdlv scales (TMS, MIDS and ODS) showed strong correlations (-0.63 to -0.69) with the SF-36 SF and moderate correlations with the SF-36 RP (-0.51 to -0.58) and SF-36 RE (-0.45 to -0.51). These results were consistent with the hypothesized associations.

The WLQ-mdlv PDS showed a weak correlation (-0.36) with the SF-36 PF, thereby not confirming the hypothesized moderate correlation.

DISCUSSION

We made an improved Dutch language version of the WLQ (WLQ-mdlv) available for use in a Dutch population and added to the evidence that the WLQ has good measurement properties. The reliability and external construct validity of the four WLQ-mdlv scales and index were confirmed in a miscellaneous sample of Dutch patients with a chronic condition experiencing work limitations. These results are consistent with studies using the original WLQ (1, 2, 11) and support its use as a measure of work limitations in Dutch patients with a physical chronic condition.

The intelligibility of the WLQ-mdlv is considered good by all participants. Recommendations for further improvement might be to bring the layout and direction of phrasing of the PDS in agreement with other scales, as also suggested by Allaire (34), and by adjusting the text in the answering possibility *'Difficult*

some of the time (about 50%)' into '*Difficult half of the time (50%)*, as reported by Burton et al. (35).

The results of this study show high internal consistency for the WLQ-mdlv scales and index scores, with values of Cronbach α that correspond with previous studies (2, 11, 36).

We found good test-retest reliability of the WLQ-mdlv. Values of SWK for individual WLQ items indicate good to excellent agreement. On the basis of excellent ICC values for WLQ-mdlv scales and index, we conclude that the WLQ-mdlv is a reliable instrument to measure changes within groups.

The negative correlations between the WLQ-mdlv index and WAI index, and SF-36 component summery scores, as well as correlations between the WLQ-mdlv scales and SF-36 scales for SF and RP or RE, confirm the external construct validity.

For use at individual level, measures should be brief and easy to administer, score, and interpret. In addition, they should be highly reproducible over time and have a small SEM for use in longitudinal monitoring (27). The WLQ-mdlv meets practical standards, and could be used in clinical practice as a reliable and valid instrument to assess experienced work limitations in individual patients. Values for SEM and MDC are satisfactory. These values inform clinicians about the magnitude of measurement error that should be taken into account when judging whether an individual's work limitations have really changed after treatment (30). On the basis of SEM values we conclude that for measuring change in individual patients the WLQ-mdlv index shows acceptable sensitivity to (individual) change but WLQ scale scores should be used with some caution.

On the basis of the variety of chronic conditions and settings, we consider this sample to be representative for the Dutch population with a chronic condition. The percentage of women (62%) and the mean score on the SF-36 general health of the study sample correspond with national data (63% female, mean score on SF-36 general health, 49.4) (37). In addition, the percentage of women also corresponds with WLQ studies in other countries (1, 2, 11, 38).

A limitation of this study is the absence of data from healthy subjects for comparison of scores on the WLQ-mdlv scales and index. Such data may help to interpret the higher values on the WLQ scales and index found in this study compared with other studies, meaning that this study population experienced more work limitations. The mean value (SD) for the WLQ index reported by Walker et al. (11) was 5.9 (5.6), whereas mean values of SF-36 PCS and MCS were consistent with values of the sample of this study. Because calculation of the WLQ index is derived from modelling the relationship of WLQ scale scores to objectively measured productivity for a population in the United States (9), the interpretation of the WLQ index in European countries may need closer examination.

This study shows higher mean scores on WLQ scales than other studies (1, 2, 11, 38). These higher values could be explained partly by the inclusion criterion 'perceived interference of the chronic condition with job performance', and by the relatively low number of working hours in the sample of this study. Only 26% of our patients worked full time; other studies reported 87% working full time or mean hours worked of 37 to 40 hours a week (1, 2, 11). In the sample of this study, patients who worked full time showed a lower value on the WLQ-mdlv index (8.4), indicating less work limitations, compared with patients who worked 12 to 23 hours per week (12.9). These findings might indicate that fewer working hours and working part time is a common accommodation for employees with a chronic condition experiencing work disability that may be important for job retention and health (5).

Items of the PDS were most frequently scored as 'Does not apply to my job', as was also reported by Walker et al. (11). These findings may explain the weak correlation between the scores on the WLQ PDS and SF-36 PF and may indicate work adjustments or job selection; people with a chronic physical condition may select jobs or tasks that do not require high physical demands. We agree with Walker et al. who suggest to score those items that 'Do not apply to my job' as having 'No limitation', because that is the case in the actual work situation (11).

The additional interviews in this study provided more insight into experienced work limitations. Some participants reported that they experienced many work limitations, but highly valued the job that they performed: *'The questionnaire indicates that I'm not able to do much work. But the 6 hours I work twice a week give me a lot of satisfaction'*.

Several participants noted that the WLQ-mdlv does not include information about work adjustments, such as reduced working hours or modified duties. On the basis of their scores, they seemed to have few work limitations; however, those scores were based on working part time whereas they used to work full time. Some respondents criticized that the WLQ-mdlv only addresses work and reported that they performed their job without limitations but experienced problems in self-care and social and leisure activities because they were exhausted after work.

Because the WLQ measures on-the-job limitations only, limitations in other domains may be neglected and job changes and adaptations are not taken into account in the WLQ scores. If the work situation is adjusted to the person's disabilities, experienced limitations could not be fully expressed in the WLQ scores. The real loss of productivity of patients with a chronic condition may therefore be underestimated (39).

When using the WLQ-mdlv in clinical practice, an additional interview can therefore provide important information about work adjustments and the impact of work limitations on activities in other domains.

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Chapter 5

A new intervention to improve work participation of young adults with physical disabilities: a feasibility study

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ABSTRACT

Aim: The aim of the study was to evaluate the feasibility of a new intervention to improve work participation of young adults with physical disabilities, addressing (1) implementation and costs and (2) preliminary effectiveness.

Method: Twelve young adults with physical disabilities (six males, six females; age 19-28y, median age 21y 6mo) participated in a 1-year multidisciplinary vocational rehabilitation intervention. In a pre-post intervention design, we assessed implementation and costs as well as preliminary effectiveness in terms of employment and occupational performance using questionnaires and interviews. We tested pre-post differences with the McNemar test for proportions and Wilcoxon signed rank test for scores on occupational performance; p-values less than 0.05 were considered statistically significant. Additionally, we assessed work participation at follow-up after 2 years and 3 years.

Results: The intervention was implemented in an outpatient rehabilitation clinic for young adults. The median cost per participant for 1 year was €3128, which is an equivalent to the cost of 72 contact hours per participant. Post-intervention, and at 2 years and 3 years follow-up, a significantly higher proportion of participants were employed (8/12 post vs 2/12 pre-intervention; $p<0.05$), with the ratio of those in paid to unpaid employment being 4:4, 5:3 and 7:1 respectively. Participants showed improved occupational performance in work, self-care, and leisure.

Interpretation: Feasibility and preliminary effectiveness of the intervention are promising. Employed participants seemed to have achieved suitable and continuous employment.

With increasing numbers of young people with physical disabilities living into adulthood, the focus of health care has moved from survival to adequate treatment to support these young adults to make the transition into adulthood and become autonomous individuals who participate in society and manage their own life. A successful transition to adulthood may reduce lifelong dependency on others, unemployment, lack of achievement, and poor quality of life (1-3).

In the process of transition to adulthood one of the challenges is to find employment. Employment provides financial independence and promotes psychological wellbeing, by structuring the day, providing social interaction and a meaningful contribution to society, and developing self-identity (4, 5). Although data on the employment situation of people with physical disabilities are not always readily comparable across countries, an employment rate of about 30% is reported in both Europe and the USA (6, 7). In the Netherlands, the employment rate among young adults (15-25y) with physical disabilities is 39% (26% and 12% in persons with moderate and severe disabilities, respectively) (8).

Young adults with physical disabilities may experience substantial difficulties in the area of employment, such as being offered work that is physically too demanding, inadequate transportation facilities, inaccessibility of buildings and toilet space, lack of assistance with personal care, reluctant attitudes among employers, lack of support, and low self-esteem (4, 5). It is reported that disabled young people would welcome support to help them find suitable employment (2, 4). Currently, there is no evidence on the effectiveness of interventions to improve work participation of this group of young adults.

Based on the literature (9-11), we designed a multidisciplinary intervention aimed at improving the work participation of young adults with physical disabilities by combining rehabilitation and vocational services, with the aim of securing suitable employment that contributes to the young disabled adults' health and well-being. The present study describes the intervention and evaluates its feasibility in young adults with physical disabilities, addressing (1) implementation and the costs of the intervention and (2) preliminary effectiveness in terms of work participation and the occupational performance of the participants.

METHOD

Participants

Twenty young adults were referred by a rehabilitation physician of the outpatient clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre to participate in the intervention. They were included in the intervention in three

consecutive intervention groups between March 2007 and May 2008. Inclusion criteria were (1) a diagnosis of a chronic condition causing physical disabilities, (2) age between 16 years and 25 years, (3) not, or not suitably, employed, and (4) completed education, or expecting to complete education within 6 months. Participants had adequate understanding of the Dutch language and no intellectual disability. Suitable employment was defined as a job that was consistent with the individual's education and physical abilities.

Participants received verbal and written information about the study and signed informed consent. The Medical Ethics Committee of Erasmus MC Rotterdam approved this study.

Intervention 'At work?!'

The multidisciplinary vocational rehabilitation intervention 'At work?!' was designed for young adults with physical disabilities entering the labour market, with the aim of improving (abilities to achieve) work participation. The key elements of the 1-year intervention were converging rehabilitation and vocational services and combining a group programme with individual assessments and coaching.

The intervention started with a group support programme consisting of six 2-hour sessions over 8 weeks, guided by an occupational therapist and a job coach. In addition, a psychologist and a social worker from the multidisciplinary rehabilitation team were involved in some group sessions, as were several experts, including a job interview trainer and 'role models' (employed young adults with a physical disability). A group was made up of 6 to 10 young adults with heterogeneous physical disabilities. Group sessions provided information and discussion about work-related topics and aimed to increase insight into personal (dis)abilities, addressing work objectives, coping strategies, occupational balance, finding a (suitable) job, how to present oneself at a job interview, and employment regulations and social security. In addition, group sessions offered opportunities to develop communication and interaction skills, to share experiences, and to increase group members' self-efficacy. Homework assignments, for example preparing a self-presentation or preparation for a job interview, contributed to active participation and planning.

Along with the group programme, individual assessments by an occupational therapist aimed to explore personal capacities and to determine personal goals for employment, using two semi-structured interviews: the Canadian Occupational Performance Measure (COPM)(12), and the Occupational Performance History Interview, version 2.0 (13). Prioritized occupational issues were translated into specific goals, for example finding a job in the catering industry, organizing work tasks, increasing computer skills, or obtaining a driving licence (to travel to

work). Following on from the group programme, participants received customized individual coaching by an occupational therapist and a job coach, with the aim of developing vocational skills and work routines, enhancing self-management skills, providing work placement opportunities and work experience, and advising on workplace modifications.

Measurements

In a pre-post intervention design, the feasibility of the intervention was evaluated, addressing implementation and costs and preliminary effectiveness. Assessments were performed at baseline and after the 1-year intervention, using questionnaires and semi-structured interviews. In addition, work participation after 2 years and 3 years was evaluated.

We collected demographic data on the study participants. Educational level was categorized as low (pre-vocational practical education or lower), medium (pre-vocational theoretical education or upper secondary vocational education), or high (secondary general education, higher professional education or university) (2). The severity of physical limitations was grouped in three levels, using z-scores on the Physical Functioning scale of the Medical Outcome Study (MOS) Short-Form Health Survey (SF-36) derived from a Dutch reference population with a chronic condition (14): severe limitations (z-score ≤ -2); moderate limitations (z-score between -1 and -2) and no limitations (z-score ≥ -1).

Implementation and costs of the intervention

Implementation of the intervention in an outpatient rehabilitation clinic for young adults was evaluated, addressing recruitment of participants and participants' satisfaction with the intervention. Post-intervention, participants rated the overall programme, the group programme and the individual coaching on a numeric rating scale from 1 (very poor) to 10 (excellent).

The costs of the intervention were determined from the healthcare provider's perspective and were based on the per-protocol principle, in accordance with which persons who participated in the feasibility study but dropped out of the intervention (n=5) were excluded from the cost analyses (15). The costs of the intervention included labour and overhead costs for the first year. Labour costs were calculated by multiplying the number of hours of professionals' time required for individual and group sessions by the corresponding unit costs. Unit costs were standardized costs per hour, which were obtained by dividing the normative income (based on collective labour agreements) by the number of working hours per year. Overhead costs were allocated to participants using a marginal mark-up percentage of 35.5%. All costs were based on 2010 euro cost data.

Preliminary effectiveness of the intervention

The primary outcome measure of effectiveness was work participation. In addition, we evaluated work ability, work limitations, occupational performance, and health-related quality of life. We expected that the work participation and occupational performance of the participants would be improved after the intervention, and that health-related quality of life would be similar or increased.

Work participation

Work participation was defined as working 12 or more hours per week, according to Statistics Netherlands (www.cbs.nl). We distinguished two categories: (1) employment, including paid and unpaid, for 12 or more hours per week, and (2) no employment, including study. Unpaid employment was included because of its value for social participation and psychological wellbeing, and because it offers daily rhythm, work experience, and entry to the work force, which could facilitate achieving paid employment (16).

Work participation was assessed using the PROductivity and DISease Questionnaire (PRODISQ), module B (occupation, income and work situation) (17). The job coach provided additional data about work participation at the 2- and 3-year follow-up.

Work ability and work limitations

The work ability and work limitations of employed participants were assessed post intervention using the Work Ability Index (WAI) and the Work Limitations Questionnaire (WLQ). The WAI is a valid measure of work ability using seven items (18). The overall WAI index score is calculated by summing the single item scores (range 7-49 points), classifying work ability as poor (7-27), moderate (28-36), good (37-43) or excellent (44-49).

The WLQ-25 is a valid measure of the impact of chronic conditions on job performance and work productivity (19, 20). Scores on 25 items generate four scale scores - time management, physical demands, mental-interpersonal demands and output demands - which indicate the amount of time during the previous 2 weeks for which the employee's ability to do the job was limited. From the four scale scores a WLQ productivity index is calculated. Higher WLQ scores indicate greater work limitations.

Occupational performance

Occupational performance was assessed using the OPHI-II (13) and the COPM (12). The OPHI-II provides both quantitative and qualitative information about occupational performance. Responses from the interview are organized in three

scales: occupational identity (11 items), occupational competence (nine items) and occupational settings (nine items). Item scores range from 1 (extreme occupational dysfunction) to 4 (exceptionally competent occupational functioning); for each scale, sum scores are calculated. The OPHI-II is a valid measure across age, diagnosis, culture and language (21).

The COPM is an individualized outcome measure that is designed to detect change over time in a person's self-perception of occupational performance in the areas of self-care, productivity and leisure. In a semi-structured interview a person selects five prioritized activities that he or she wants, needs or is expected to perform and rates current performance and satisfaction with performance on a 10-point scale, from 1 (not able to do it/not satisfied at all) to 10 (able to do it extremely well/extremely satisfied). Subscale scores for performance and satisfaction are calculated by dividing the sum of the issue ratings by the number of issues.

Post intervention, the prioritized issues were re-scored; participants were blinded to the previous scoring. The COPM is a valid and reliable measure that is sensitive to change; in addition, it is appropriate for young adults with physical disabilities (2). Individual changes of two or more points are considered clinically important (12).

Health-related quality of life

Health-related quality of life was assessed using the MOS SF-36 (22). Responses on the 36 questions are organised into eight subscales. In addition, scores are summarized in the Physical Component Summary (PCS) and Mental Component Summary (MCS), which are normally distributed with a mean of 50 (SD 10) (22). The Dutch language version of the SF-36 is well validated for use in populations with chronic diseases (14).

Statistical analyses

Data were analysed using IBM SPSS Statistics software version 16.0. Individuals who completed the intervention (n=12) were included in the analysis; post intervention data on secondary outcomes were missing for one of these individuals. Because of the small study sample size, non-parametric tests were used; p-values less than 0.05 were considered statistically significant.

Results were summarised using medians and interquartile range (IQR). The number of hours and the costs of the intervention for each participant (median, IQR) were calculated.

We used the McNemar test to compare the proportion of participants employed or unemployed pre and post intervention, and the Wilcoxon signed rank test to compare pre- and post-intervention scores on the OPHI-II, COPM and SF-36.

RESULTS

Seventeen persons participated in the feasibility study, including one participant aged 28 years but who fulfilled other inclusion criteria. Three other participants in the intervention did not participate in the feasibility study: one did not complete education within 12 months and two did not provide informed consent.

Four participants dropped out of the intervention after the first group session because of severe health problems (n=2), personal problems (n=1) or an unknown reason (n=1); a fifth person dropped out after completing the group programme owing to non-compliance with agreements.

Table I presents the characteristics of the study sample (n=12, six males and six females with a median age of 21y 6mo). Eight out of 12 had a medium level of education and six persons were severely limited in physical functioning, of whom four were wheelchair dependent.

Implementation and costs of the intervention

The intervention was implemented in the outpatient rehabilitation clinic for young adults by starting two new groups per year. The diagnostically heterogeneous intervention groups facilitated the recruitment of participants, and were evaluated as beneficial by participants and professionals. Participants and professionals were very satisfied about the converging of rehabilitation and vocational services within the intervention, and the combination of a group and an individual programme. Participants rated (median, IQR) the overall programme as 8.0 (1.0), the group programme as 7.3 (1.0) and the individual sessions as 8.8 (1.3). These ratings were not correlated with outcomes on work participation.

Using the per-protocol principle, costs were determined for 12 participants who completed the intervention. Table II gives an overview of the costs of the intervention per participant for the first year. Providing the group programme required a total of 150 hours for three groups for supervision and organization of the sessions by an occupational therapist and job coach (both 19h per group) and other experts (12h per group). In addition to individual pre- and post-intervention assessments (total 73h), six participants needed individual occupational therapy for a total of 103 hours. All participants required individual job coaching on job placement for 1 year (15-90h per person) and additional coaching on the job

Table I Characteristics of the study participants (n=12)

Median age in years (IQR, range)	21.5 (4.0; 19-28)
Male/female (n)	6/6
Chronic condition (n)	
Cerebral palsy	4
Muscular disease	2
Spinal cord injury	1
Traumatic brain injury	2
Multiple sclerosis	1
Spina bifida	1
Chronic obstructive pulmonary disease	1
Onset of chronic condition	
Birth	6
Before age 12 years	3
Between age 12-18 years	1
After 18th birthday	2
Living situation	
Living with parent(s)	8
Living on their own	4
Level of education[b]	
Low	2
Medium	8
High	2
Physical Functioning[a]	
Severe limitations	6
Moderate limitations	4
No limitations	2
Period looking for employment	
Not yet	6
< 1 year	3
1-2 years	1
> 2 years	2

[a] Domain scores were compared with a Dutch reference population with a chronic condition from Aaronson et al.[14] [b] See Measurement section for definitions. IQR, interquartile range.

Table II Costs of the intervention per participant for the first year (n=12) (euros, 2010)

			Total number of hours	Median (IQR) number of hours	Unit costs (euros, 2010)[a]	Median (IQR) costs per participant (euros, 2010)
Labour costs						**2308.72 (949.29)**
Consultation physician	Rehabilitation physician		12	1.00 (-)	88.06	88.06
Assessments (pre-post)	Occupational therapist		73	6.00 (-)	33.64	201.84
Group programme[b]	Total		150			397.80
		Occupational therapist	*57*	*4.75 (-)*	*33.64*	
		Job coach	*57*	*4.75 (-)*	*30.85*	
		Other experts	*36*	*3.00 (-)*	*30.49*	
Individual job coaching	Job coach		520	45.00 (28.5)	30.85	1388.25 (879.23)
Individual occupational therapy	Occupational therapist		103	3.0 (12.0)	33.64	100.92 (403.68)
Overhead costs[15]						**819.60 (337.00)**
Total costs						**3128.32 (1286.30)**

[a] Collective labour agreements (Occupational therapist: CAO University Medical Centres scale 9; job coach: CAO social work scale 8; for other experts CAO University Medical Centres scale 8 is applied). [b] Based on three groups, and per-protocol-analysis (n=12). IQR, interquartile range.

(about 40h a year). Drop-outs incurred few expenses, as they withdrew very early in the programme.

Individual and group sessions required a total of 858 hours labour over 1 year, or 72 hours per participant: 59 hours on individual and 13 hours on group sessions. Of these hours, 48 hours were charged to the Dutch Employee Benefits Insurance Authority (UWV) for job coaching, and 24 hours were at the expense of (usual) healthcare insurance.

Median (IQR) labour costs were €2308.72 (€949.29) per participant; median overhead costs were determined at €819.60, which summed to total median (IQR) costs of €3128.32 (€1286.30) for the intervention per participant for the first year. Median additional costs for job coaching until the 2-year follow-up were €1380 per participant, equivalent to a median of 33 hours, required by nine participants.

Preliminary effectiveness of the intervention

Work participation

Before the intervention, two participants (2/12) were employed in unpaid or unsuitable employment. Post intervention, eight participants (8/12) were employed, meaning that a significantly higher proportion of young adults participated in employment compared to pre intervention (McNemar test, p=0.031; Fig. 1). The ratio of those in paid employment to those in unpaid employment was 4:4. Participants worked 12 to 32 hours per week (median 18 h/wk), and had a broad variety of jobs, mainly low to medium level, corresponding to their

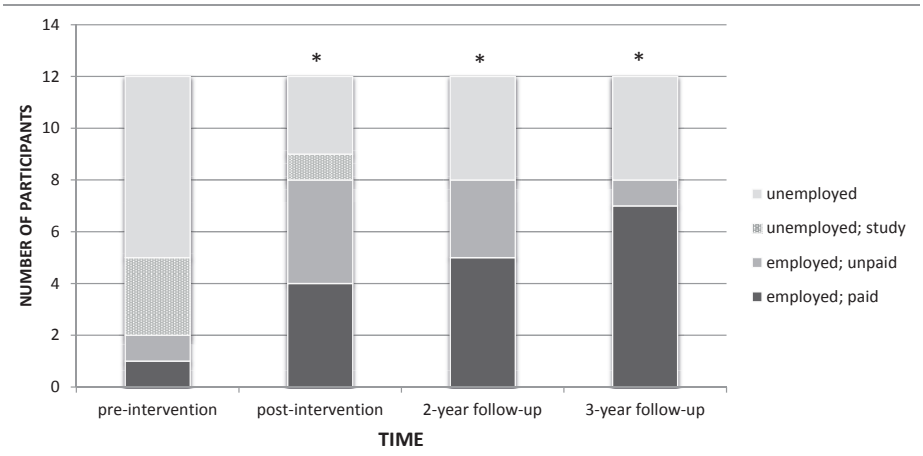

Figure 1 Work participation at pre-intervention, post intervention, and at 2- and 3-year follow-up

educational level, e.g. office clerk, kitchen aid, museum guard, help-desk worker, graphic designer, and shop assistant.

Three persons did not achieve employment because they were undertaking a course or study to improve employment opportunities (n=1) or because increased health problems interfered with work performance (n=2), e.g. increased fatigue caused by multiple sclerosis.

At the 2-year follow-up, eight participants were employed, with a ratio of paid to unpaid employment of 5:3. Two individuals were no longer pursuing employment because working increased their health problems. At the 3-year follow-up seven participants were in paid employment; one other person was working unpaid. Two of four unemployed participants were looking for a job; one of them after being employed for 18 months. Six of eight participants who achieved employment post intervention were still employed at the 2-year follow-up (paid/unpaid: 4/2) and five were still employed at the 3-year follow-up (paid/unpaid: 5/0). Two of them had been looking for a job for more than 2 years before the intervention. These findings indicate that their work participation seems to be continuous and long term. Two participants no longer received a disability pension; for others, the disability pension was reduced substantially, as a supplement to their work income.

Work ability, work limitations, occupational performance and health-related quality of life

Post intervention, employed participants showed moderate work ability with median scores on the WAI index of 31.0 (IQR 3.0). They were limited on the job for 20 to 33% of the time according to their scores on the WLQ scales (see Table III).

Participants showed improved occupational performance, as demonstrated by a significant improvement on OPHI-II total scores (Wilcoxon signed rank test; Z=-2.6, p=0.009), OPHI-II scales for occupational identity (Z=-2.9, p=0.003) and occupational competence (Z=-2.4, p=0.02); COPM Performance scores (Z=-2.3, p=0.02) and COPM Satisfaction scores (Z=-2.3, p=0.02). Higher occupational identity and occupational competence scores indicated that participants displayed more positive values and interests and had a more positive image of the future, as well as an increased ability to display productive and satisfying occupational behaviour.

Improved occupational performance and satisfaction with performance of prioritized issues (COPM) addressed issues in all three areas of occupational performance – productivity, self-care, and leisure. Four participants achieved a change of two points or more on performance scores, indicating clinically impor-

Table III Work ability, work limitations, occupational performance and health related quality of life pre and post intervention

	Pre intervention, median (IQR)	Post intervention, median (IQR)
Number of participants	12	11
WAI index[a]	--	31.0 (3.0)
WLQ[a] Time Management	--	25.0 (23.8)
WLQ[a] Physical Demands	--	21.9 (17.1)
WLQ[a] Mental-Interpersonal Demands	--	19.4 (45.5)
WLQ[a] Output Demands	--	20.0 (33.8)
WLQ[a] index	--	5.8 (11.3)
OPHI-II Total Score	70.5 (10.8)	82.0 (22.0)*
Occupational Identity Scale (OIS)	27.0 (7.0)	33.0 (9.0)*
Occupational Competence Scale (OCS)	22.5 (3.8)	24.0 (5.0)*
Occupational Settings Scale (OSS)	22.0 (4.5)	30.0 (7.0)
COPM Performance Subscale	4.9 (2.5)	7.0 (2.4)*
Performance Productivity (n=7)	*5.5 (4.5)*	*7.0 (3.5)*
Performance Self-care (n=6)	*5.0 (2.5)*	*6.5 (2.2)*
Performance Leisure (n=5)	*5.0 (2.5)*	*7.0 (2.5)*
COPM Satisfaction Subscale	3.6 (3.3)	7.0 (2.5)*
Satisfaction Productivity (n=7)	*5.0 (4.5)*	*7.0 (3.0)*
Satisfaction Self-care (n=6)	*3.8 (3.9)*	*5.8 (2.4)*
Satisfaction Leisure (n=5)	*4.0 (2.5)*	*7.0 (3.5)*
SF-36		
Physical Component Summary (PCS)	33.7 (19.3)	37.8 (13.3)
Mental Component Summary (MCS)	50.2 (21.3)	49.5 (13.6)

[a] n=7; only employed persons completed the WAI and the WLQ.
* p<0.05; Wilcoxon signed rank test. WAI, Work Ability Index; WLQ, Work Limitations Questionnaire; OPHI-II, Occupational Performance History Interview; COPM, Canadian Occupational Performance Measure; SF-36, Medical Outcome Study 36-item Short-Form Health Survey.

tant change, and seven achieved a change of two or more points on satisfaction scores.

The health-related quality of life of participants did not change after the intervention, based on scores on component summery scores on the physical and mental health domains of the SF-36; this was confirmed for employed participants in a sub-analysis. Post-intervention physical health of participants was significantly worse compared with an age-appropriate Dutch reference sample (20-29y) (37.8 vs 53.1; one-sample Wilcoxon signed rank test, p=0.006), indicating that the physical health status of participants was poor (23).

DISCUSSION

It appeared feasible to implement a 1-year multidisciplinary intervention to improve the work participation of young adults with physical disabilities in an outpatient rehabilitation clinic for young adults. Twice a year a new group starts the intervention, converging rehabilitation and vocational services in a group programme and individual coaching. The total median costs of €3128 per participant for the first year, and median additional costs of €1380 until the 2-year follow-up, are lower than the standard amount for an individual reintegration agreement (unemployment assistance benefit (IRO)) of €5000 (2008-2010) and are considered reasonable, given the results. Since participants are young, the financial benefits of paid employment may have long-lasting effects, both increasing their autonomy and decreasing the financial burden for society. Preliminary results show that work participation improved substantially after the intervention. In addition to the primary outcome on work participation, we explored some other aspects of employment, such as work ability and work limitations as well as other domains of occupational performance (self-care and leisure). In the absence of a control group, however, we do not know how work participation would have developed without the intervention, considering that young adults might be expected to gain employment as an age-appropriate transition. A further limitation of this study is the small sample size.

Most participants in this study had moderate or severe limitations of physical functioning and some also had a low educational level, both of which are considered to be factors hindering the chance of employment for young disabled individuals (5, 24). Despite their severe physical limitations, those achieving employment showed moderate work ability and work limitations, indicating that their work tasks and conditions matched their abilities and were not physically too demanding, according to their scores on the WLQ Physical Demands scale. The convergence of rehabilitation, providing insight in their physical skills and capabilities, and job coaching, providing suitable employment positions and on-the job-training, might have contributed to achieving suitable employment. Thus, a good fit between person (abilities and needs) and environment (job demands and support) seemed to be reached.

Post intervention, improved occupational performance and satisfaction with performance of prioritized issues (COPM) were not restricted to the area of productivity, but also addressed self-care and leisure activities. The goal of employment seemed to motivate participants to resolve problems in other areas which they previously disregarded or refused to address, e.g. ergonomic adjustments of their wheelchair, independent toilet use, or using public transport. Thus, employ-

ment can be an important outcome for young adults, and may encourage them to improve their occupational performance in other areas. These results will have to be interpreted with caution, since the number of analyses carried out was large relative to the small sample size. However, the findings are in line with the broad integrated approach of the intervention, and are consistent with others reporting that self-care independence and mobility might be important factors for enabling work participation among young adults with physical disabilities (4, 24).

To our knowledge, there is no literature on the effectiveness of vocational interventions specifically targeting young adults with physical disabilities. Considering that 25% of the young disabled people receiving disability employment benefit in the Netherlands ('Wajong') achieved employment in 2008, and that the Dutch Employee Benefits Insurance Authority (UWV) considers a rate of 25% achieving paid employment as an indicator of successful job coaching in this population (25), we consider a 34% paid employment rate after 1 year in our sample as a successful result. The long-term results, indicating that employment continued in most cases, and that the number in paid employment further increased, seem to be favourable. A high dropout rate of the intervention should be anticipated, which might be inevitable in the target population given the high burden of their chronic condition and a lower compliance in this age group.

In conclusion, the feasibility and preliminary effectiveness of the intervention, converging rehabilitation and vocational services, are promising. Post intervention, a substantial proportion of the young adults was employed, and they seemed to have achieved suitable and continuous employment, and participants showed improved occupational performance. The goal of employment and the broad integrated approach of the intervention seemed to support young adults to resolve issues in work, as well as in self-care and leisure. Future research in a larger sample and a controlled study design will add to the evidence for the effectiveness of the intervention.

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Chapter 6

Improved occupational performance of young adults with a physical disability after a vocational rehabilitation intervention

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ABSTRACT

Purpose: The purpose of this study was to investigate into more detail how occupational performance of participants of a 1-year multidisciplinary vocational rehabilitation intervention changed over time, using a broad focus on three areas of occupational performance, addressing work, as well as self-care and leisure. In addition, we explored differences between employed and unemployed persons.

Methods: In a pre-post-intervention design, changes in occupational performance, addressing work, self-care and leisure, were evaluated using the Canadian Occupational Performance Measure (COPM) and the Occupational Performance History Interview (OPHI-II).

Results: Eleven young adults (median 22 years) with physical disabilities participated. Post-intervention, participants experienced fewer problems and showed improved occupational performance in work, as well as self-care and leisure, and improved satisfaction with performance. Participants also showed improved occupational identity and occupational competence, and total scores on OPHI-II. Participants who did not achieve employment did not differ in demographic characteristics. They experienced problems in all three areas of occupational performance pre-intervention, and more difficulty in interacting in occupational settings (environment). Post-intervention, their levels of occupational identity, competence and environment were similar to those of employed persons.

Conclusions: Participants showed improved occupational performance after the intervention. The goal of employment and the broad integrated approach of the intervention seemed to motivate participants to resolve problems in work, as well as self-care and leisure. Unemployed persons faced problems in all three areas of occupational performance at start. Although they seemed to catch up during the intervention, they did not achieve employment within 1 year.

INTRODUCTION

An increasing number of youth with physical disabilities living into adulthood, face the challenge of becoming independent adults in society. Adolescence is the key age for developing life skills and improving autonomy and social participation. Rehabilitation care may contribute to a successful transition of young people into adulthood, by enabling persons with disabilities to perform meaningful roles and to participate in society. This may result in optimal participation and a fulfilling life at adult age, and prevent lifelong dependency, unemployment, lack of achievement, and poor quality of life [1-8].

Participation in society and occupational performance are important and interdependent outcomes for rehabilitation for improving the health and well-being of young adults [1, 9]. Participation concerns a person's involvement in life situations [10], and is described as a pattern of life that is personally relevant, acceptable, meaningful and supported in society [11]. Occupational performance refers to choosing and performing meaningful occupations in the areas of work, self-care and leisure, and addresses a person's self-perception of performance as well as satisfaction with performance [12].

Participation in work is considered important to take part in society and for financial independence. However, young adults with physical disabilities experience considerable difficulties with participating in work, and feel strongly restricted in this area [4, 7, 13-16].

We designed a 1-year multidisciplinary vocational rehabilitation intervention to support young adults with physical disabilities to achieve work participation. The intervention was implemented in an outpatient rehabilitation clinic for young adults. A feasibility study demonstrated that 8 of 12 persons (67%) participated in paid or unpaid work after one year and that participants showed improved occupational performance [17].

The present study aimed to investigate into more detail how occupational performance of participants of the vocational rehabilitation intervention changed over time, using a broad focus on three areas of occupational performance, addressing work, as well as self-care and leisure. In addition, we explored differences between persons who were employed and unemployed after the intervention.

METHODS

Participants

Twenty young adults (10 males, 10 females) with physical disabilities were included in the intervention in sequential order in three consecutive intervention groups between March 2007 and May 2008, after referral by a rehabilitation physician of the young adult teams of Erasmus MC and Rijndam Rehabilitation Centre, Rotterdam. Participants were diagnosed with a chronic condition that caused physical disabilities, were not (or not suitably) employed, aged between 16 and 25 years, and had finished education or were finishing education within 6 months. In addition, they had sufficient understanding of the Dutch language, and no intellectual disability. Suitable employment was interpreted as a job that was appropriate for a person's education and that he was physically able to perform, and was established by the job coach and occupational therapist based on the pre-intervention assessments.

Seventeen of the participants were included in the feasibility study. Of these, four dropped out from the intervention after the first group session, and one person after completing the group program. For one other person post-intervention interviews were missing, leaving 11 participants (6 males, 5 females) for analyses of pre- and post-intervention interview data that are described in the present paper [17]. Characteristics of the study sample are presented in Table 1. Median age of the participants was 22 years; the majority had a medium level of education. Five persons were severely limited in physical functioning, of whom four where wheelchair-dependent.

Study participants received verbal and written information about the study and signed informed consent. The Medical Ethics Committee of Erasmus MC Rotterdam approved the study.

Intervention 'At work?!'

The multidisciplinary vocational rehabilitation intervention 'At work?!' was designed for young adults with physical disabilities entering the labor market, aiming to improve (abilities to achieve) work participation. The 1-year intervention converged rehabilitation and vocational services, and combined a group program with individual assessments and coaching [17].

The intervention addressed motivation for employment, productive roles and routines and vocational skills, based on the Model Of Human Occupation (MOHO) [18]. The concept of occupational balance, implying a healthy balance of work, leisure and self-care, was used to pursue suitable employment that matches with the young adult's abilities and contributes to health and well-being. In addition,

Table 1 Pre-intervention characteristics of the study participants (n=11), in relation to post-intervention results

	Pre-intervention characteristics	*Post-intervention results*	
	Study sample (n=11)	*Employed (n=8)*	*Unemployed (n=3)*
Age in years (median, IQR)	22 (4)	21 (5)	24 (-)
Male participants (n)	6	5	1
Chronic condition (n)			
Cerebral palsy	3	2	1
Muscular disease	2	2	-
Traumatic brain injury	2	2	-
Spina bifida	1	1	-
Spinal cord injury	1	-	1
Multiple sclerosis	1	-	1
Chronic obstructive pulmonary disease	1	1	-
Onset of chronic condition (n)			
Birth	5	4	1
Before age of 12 years	3	3	-
Between age 12 and 18 years	1	-	1
After 18th birthday	2	1	1
Living situation (n)			
Living with parent(s)	8	7	1
Living on their own	3	1	2
Level of education (n)			
Low	2	2	-
Medium	7	5	2
High	2	1	1
Physical Functioning[a]			
Severe limitations	5	3	2
Moderate limitations	4	3	1
No limitations	2	2	-
Period looking for employment (n)			
Not yet	5	5	-
< 1 year	3	1	2
1-2 years	1	-	1
> 2 years	2	2	-

[a] Domain scores were compared with a Dutch reference population with a chronic condition from Aaronson et al.[22]

Table 2 Outline Intervention program 'At work?!'

Week	Group	Individual	Homework Assignments
Wk 1	**Session 1: Introduction** – Persons and program – Experiences/advice from a working young adult with physical disabilities	**Assessment**: – COPM – Vocational interview – Questionnaire (PRODISQ, SF-36)	• Self-presentation • Work objectives • Needs and wishes for training
Wk 2	**S 2: Work and Health** – Personal coping style – Coping with health problems in work situation (group discussion)		• Utrecht Coping List • Personal strengths and weaknesses
Wk 3		OPHI-II interview	
Wk 4	**S 3: Occupational Balance** – Interests and abilities – Work, self-care, leisure		• Occupational profile • Future goals, based on OPHI-II life history graph
Wk 5	**S 4: Finding a suitable job** – Looking for vacancies – Job demands and physical (dis)abilities		• Look for vacancies • Write a resume (CV)
Wk 6		Feedback CV	
Wk 7	**S 5: Job interview training** – Individual job interview (with unknown trainer) – Feedback on presenting yourself		• Write an application letter • Prepare a job interview
Wk 8	**S 6: Information market** – Rules and regulations, organizations, support – Evaluation and continuation		• Consider work adjustments, support, supplies you might need • Formulate questions
Wks 9-52		**Coaching**, addressing: – Job placement – Training of (vocational & self-management) skills – Coaching on the job – Work adjustments or workplace adaptations – Balancing work and other roles/activities	
Wk 52		**Assessment**: • COPM • OPHI-II • Questionnaire (SF-36, PRODISQ, WAI, WLQ)	

the concept of empowerment was used to support young adults to define personal goals and to increase their autonomy by developing knowledge, skills and awareness of values and needs [19].

The intervention started with a group support program with 6 2-h sessions in 8 weeks, guided by an occupational therapist and a job coach. In addition, a psychologist and a social worker from the multidisciplinary rehabilitation team were involved in some sessions, as were other experts, including a job-interview trainer and 'role models' of employed young adults with a physical disability. A group consisted of 6-10 young adults with heterogeneous physical disabilities. Group sessions were designed to provide information addressing general work-related topics and to encourage active participation and discussion among participants. Group discussions and the use of role models aimed to empower the young adults and to increase insight into personal (dis)abilities [19]. In addition, group sessions offered opportunities to develop communication and interaction skills, to increase a person's self-efficacy and to share experiences. Homework assignments contributed to active participation and planning. Table 2 presents an outline of the intervention, including the topics of the group sessions.

Along with the group program, individual assessments by an occupational therapist aimed to explore personal capacities and to determine personal goals for employment, using the Canadian Occupational Performance Measure (COPM) and the Occupational Performance History Interview (OPHI) [12, 20]. Prioritized occupational issues were translated into personal goals, e.g. paid employment, increasing computer skills and using public transport.

After completion of the group program, participants received individual coaching by a job coach and an occupational therapist. Content, number, frequency and duration of individual sessions were adjusted to individual needs. Individual coaching addressed developing vocational skills and work routines, enhancing self-management skills [21], providing work placement opportunities and work experience, and advising work place modifications. Participants were free to choose their job coach or occupational therapist for individual coaching.

Measures

Data on demographic characteristics were collected. Three levels of education were distinguished: low: pre-vocational practical education or lower; medium: pre-vocational theoretical education or upper secondary vocational education; and high: secondary general education, higher professional education or university [13]. Severity of physical limitations was categorized in three levels, based on participants' scores on the Physical Functioning scale of the MOS Short-Form

Health Survey (SF-36), discerning: severe limitations (PF<37.8); moderate limitations (37.8<PF<61.8) and no limitations (PF>61.8) [17, 22].

In a pre-post-intervention design occupational performance was explored at baseline (pre intervention) and after one year (post intervention), using two semi-structured interviews. Interviews were conducted by the occupational therapist, as part of the intervention and consistent with usual clinical practice.

The COPM [12] is designed to detect change in a persons' self-perception of occupational performance in the areas of self-care, productivity and leisure, over time. Each area includes three activity domains (see Table 3). The interview encourages a person to select the five most important issues or problems in activities that he wants, needs or is expected to perform and to rate current performance and satisfaction on a 10-point scale from 'not able to do it'/'not satisfied at all' (score 1) to 'able to do it extremely well'/'extremely satisfied' (score 10). To calculate subscale scores for Performance and Satisfaction, problem ratings are summed and divided by the number of problems. Post-intervention, the COPM-interview was repeated, to assess current issues in occupational performance. After that, the prioritized issues of the pre-intervention interview were rescored; participants were blinded for the previous scoring. The COPM is an individualized outcome measure, comparing a persons' assessment and reassessment scores. Score changes of two or more points are considered clinically important. The COPM has good validity, moderate test-retest and interrater reliability and is sensitive to change [12, 23], and is useful for young adults with physical disabilities [24].

The OPHI-II [20] was designed to assess occupational adaption, and gathers information about a person's past and present occupational performance in work, leisure and daily living activities. Responses are organised in three rating scales, reflecting three aspects of occupational adaptation: occupational identity (11 items), occupational competence (9 items) and occupational settings (9 items). The occupational identity scale measures the degree to which persons have values, interests and confidence, and hold an image of the kind of life desired; the occupational competence scale measures the degree to which a person is able to sustain a productive and satisfying pattern of occupational behaviour, and the occupational behaviour settings scale measures the influence of the environment on a person's occupational performance [25]. Responses are scored using a four-point scale ranging from 'extreme occupational dysfunction' (score 1) to 'exceptionally competent occupational functioning' (score 4); for each scale sum scores are calculated. Additionally, a visual representation of the life history narrative is created by plotting a person's major (positive and negative) life events on a timeline [18, 26]. Progressive narratives demonstrate a clear upward

Table 3 Experienced problems in areas of occupational performance of the COPM pre- and post-intervention

	COPM	(Re)scored prioritized problems								Repeated inventory of problems			
		Pre-intervention				Post-intervention				Pre-intervention		Post-intervention	
	No. of 1-5 prioritized problems	Performance		Satisfaction		Performance		Satisfaction		No. of persons reporting a problem[a]	No. of problems reported	No. of persons reporting a problem[b]	No of problems reported
		median	IQR	median	IQR	median	IQR	median	IQR				
Productivity										**8**	**14**	**8**	**9**
Paid or unpaid work*	7	5.5	(2.7)	3.5	(3.5)	7.0	(3.0)	7.5	(2.3)	8	10	6	7
Household management	1	5.0	(-)	5.0	(-)	6.0	(-)	6.0	(-)	2	2	1	1
Play/school	2	7.5	(-)	7.5	(-)	6.0	(-)	5.5	(-)	2	2	1	1
Self-care										**8**	**23**	**5**	**10**
Personal care	3	4.0	(-)	4.0	(-)	5.0	(-)	5.0	(-)	6	8	2	2
Functional mobility	6	5.0	(3.5)	3.5	(4.5)	6.0	(1.3)	6.0	(2.5)	7	12	5	7
Community management	2	4.0	(-)	3.0	(-)	4.5	(-)	5.0	(-)	3	3	1	1
Leisure										**5**	**10**	**6**	**10**
Quiet recreation	0	-	(-)	-	(-)	-	(-)	-	(-)	0	0	1	1
Active recreation	3	4.0	(-)	2.5	(-)	8.0	(-)	8.5	(-)	3	5	5	7
Socialization	3	5.0	(-)	3.0	(-)	7.8	(-)	6.8	(-)	4	5	2	2
Performance subscale*		**4.8**	**(2.4)**			**7.0**	**(2.3)**						
Satisfaction subscale*				**3.6**	**(2.9)**			**7.0**	**(2.5)**				
Total no. of problems										**10**	**47**	**10**	**29**

[a] one person reported no problems

[b] one (other) person reported no problems (after achieving employment)

*p<.05

turn, meaning life has changed for the better; regressive narratives demonstrate a clear downward turn, and stable narratives demonstrate that life remains essentially the same over time. The OPHI-II has shown to be a valid measure across age, diagnosis, culture and language [27].

Data analysis

Results were summarized using descriptive statistics. Scores for COPM subscales and OPHI-II scales were calculated (median, IQR).

Reported problems on the COPM were presented as frequencies (number of problems, number of persons reporting a problem, number of persons reporting a problem as number one priority).

Qualitative data from COPM and audio-taped OPHI-II interviews were summarized and categorized within the three areas of occupational performance: work/productivity, self-care and leisure. Narratives from the OPHI-II interviews were classified as progressive, regressive or stable.

Differences between pre- and post-intervention scores on COPM and OPHI-II were tested using Wilcoxon signed rank test. Additionally, we compared demographic characteristics of employed and unemployed participants using the Mann-Whitney U test. Patterns in the life history narratives were visually examined.

Because of the small study sample non-parametric tests were used. Tests were considered statistically significant if $p < 0.05$ (two-tailed). Data were analysed using SPSS 16.0.

RESULTS

Changes in occupational performance

Pre-intervention, two participants (16%) had unpaid or unsuitable employment. Post-intervention eight participants (67%) achieved paid (n=4) or unpaid (n=4) employment for 12-32 h/week (mean 20 h/week). Three persons did not achieve employment; reasons were undertaking a study (n=1) for better employment opportunities; and increased health problems (n=2) interfering with work performance. For one of the latter persons employment seemed to be unrealistic, due to fatigue caused by multiple sclerosis. Post-intervention results matched with pre-intervention formulated goals of all eight participants with paid or unpaid employment, and for one out of three participants who did not achieve employment.

Pre-intervention, eight persons experienced problems in more than one area of occupational performance, two persons only experienced problems with work, and one person experienced no problems. Post-intervention, participants showed improved median (IQR) performance [7.0 (2.3) versus 4.8 (2.4)] (Z=-2.25, p=0.02) and median (IQR) satisfaction with performance [7.0 (2.5) versus 3.6 (2.9)] (Z=-2.31, p=0.02) regarding the prioritized problems they rated on the COPM (Table 3). In addition, in the activity domain 'paid or unpaid work' they showed improved median (IQR) performance [7.0 (3.0) versus 5.5 (2.7)] (Z=-2.04, p=0.04) and median (IQR) satisfaction with performance [7.5 (2.3) versus 3.5 (3.5)] (Z=-2.03, p=0.04).

The total number of experienced problems decreased from 47 pre intervention to 29 post-intervention; most problems addressed functional mobility and work. Four persons showed individual change of ≥ 2 points on Performance scores, indicating clinically important change; among them one person that did not achieve employment. Seven persons showed individual change of ≥ 2 points on Satisfaction scores, including all three unemployed persons.

Also on the OPHI-II participants showed improvement on overall occupational performance in median (IQR) total scores [83 (22) versus 68 (11)] (Z=-2.63, p=0.009), as well as on median (IQR) scores for occupational identity [33 (9) versus 27 (6)] (Z=-2.94, p=0.003) and occupational competence [24 (5) versus 22 (4)] (Z=-2.36, p=0.02) (Table 4). This indicated increased expectations of success and improved estimation of possibilities and limitations, as well as an increased ability to display goal-orientated behaviour and to meet expectations.

The life history narratives of nine persons showed no changes in the progressive pattern; for one person a regressive narrative changed into progressive when finding a temporary job; for another person a progressive narrative changed into a regressive one when looking for a job after graduating, which required considerably more time than expected.

Changes in the three areas of occupational performance are described in more detail below, merging qualitative data from both COPM and OPHI-II.

Table 4 Pre- and post-intervention scores on OPHI-II items and scales

	Pre-intervention		Post- intervention	
	median	IQR	median	IQR
Occupational Identity Scale (OIS)**	**27**	**(6)**	**33**	**(9)**
*Has personal goals and projects**	3	(1)	3	(1)
Identifies a desired occupational lifestyle	3	(1)	3	(2)
*Expects success**	2	(1)	3	(2)
*Accepts responsibility***	3	(1)	3	(1)
*Appraises abilities and limitations **	2	(1)	3	(1)
Has commitments and values	3	(1)	3	(1)
Recognizes identity and obligations	2	(1)	3	(2)
*Has interests***	3	(1)	4	(1)
Felt effective (past)	2	(1)	3	(1)
Found meaning and satisfaction in lifestyle (past)	2	(1)	3	(1)
Made occupational choices (past)	3	(1)	3	(1)
Occupational Competence Scale (OCS)*	**22**	**(4)**	**24**	**(5)**
Maintains satisfying lifestyle	2	(1)	3	(1)
Fulfils role expectations	2	(1)	3	(1)
Works toward goals	2	(1)	3	(0)
*Meets personal performance standards**	2	(1)	3	(1)
*Organizes time for responsibilities**	2	(1)	3	(0)
*Participates in interests**	3	(1)	4	(2)
Fulfilled roles (past)	2	(1)	2	(1)
Maintained habits (past)	3	(1)	3	(1)
Achieved satisfaction (past)	2	(1)	3	(1)
Occupational Settings Scale (OSS)	**22**	**(5)**	**30**	**(7)**
Occupational forms: home life	3	(0)	3	(1)
*Occupational forms: (major) productive role**	2	(1)	3	(2)
Occupational forms: leisure	3	(1)	3	(2)
*Social group: home life**	3	(0)	3	(1)
Social group: productive role	2	(3)	3	(1)
*Social group: leisure**	3	(3)	3	(2)
*Physical spaces, objects and resources: home life**	3	(0)	3	(1)
Physical spaces, objects, resources: productive role	3	(3)	3	(0)
Physical spaces, objects and resources: leisure	3	(1)	3	(1)
OPHI-II TOTAL SCORE**	**68**	**(11)**	**82**	**(22)**

* $p<0.05$, ** $p<0.01$

Scoring:

4 = exceptionally competent occupational functioning;

3 = appropriate, satisfactory occupational functioning;

2 = some occupational dysfunction;

1 = extreme occupational dysfunction

Work/productivity

Pre-intervention, all participants had some experience with a worker role, whether from a part time or holiday job (n=6), internship (n=4) or volunteer work (n=1). They considered employment to be important for earning money, and feeling appreciated or valued. The most frequently experienced problem regarding work was actually finding a job (n=8); four participants rated this problem as number one priority.

Post-intervention, participants indicated more, and more specifically defined goals for employment, such as an administrative job, regular (paid) employment, employment for 28 h/week, extending working hours from 12 to 20 h/week, or a job with working hours from 10 AM to 3 PM. They considered employment not only important to gain money and respect, but also to have valuable and rewarding tasks that provide satisfaction and pleasure, for social contacts, and for their continuing development.

Post-intervention, five employed participants experienced problems in 'paid or unpaid work'; they reported problems with regular (paid) employment, asking for help, and organizing work tasks.

Self-care

Pre intervention, eight participants lived with their parents. Problems in self-care mostly concerned functional mobility, like outdoor mobility (n=4), using public transportation (n=2), driving a car (n=2), climbing stairs (n=2), and accessibility of buildings (n=1). Three persons rated problems in functional mobility as their number one priority. Three persons reported toilet use as an important problem in personal care; one of them rated this problem as his number one priority.

Post-intervention, three participants had made a transition to living on their own; they also achieved employment. The number of experienced problems in the area of self-care decreased from 23 to 10. Two persons no longer reported problems with toilet use. For three out of five employed persons who experienced problems in self-care pre intervention these problems were solved. Unemployed persons experienced a decreased number of problems in functional mobility, but they still experienced problems with using public transportation (n=2) and toilet use (n=1).

Leisure

Pre intervention, the most reported leisure activities were using the computer (n=7), watching television (n=5), listening to music (n=2) or reading books or magazines (n=2); home was the main setting for leisure (n=9). Family members (n=10) or a partner (n=1) were the most important persons in their lives. Outdoor

leisure activities were horse riding, scouting, dancing or going to the movies, theatre or a football match. Five participants were member of an organization (n=3) or sports club (n=2). One person rated problems in social contacts as his number one priority.

Post-intervention, participants showed increased participation in activities that they found interesting and they reported more outdoor leisure activities and more social contacts with age mates. Two persons reengaged in a club (for dancing and drama, respectively). Fewer persons reported 'home' as their main leisure setting (n=2). The computer remained important for leisure and communication. Two unemployed persons still experienced problems with going out; three employed persons experienced problems with sport and going on a holiday (without parents) post-intervention. This increased involvement in leisure activities may explain the increased number of reported problems in active recreation, along with improved performance and satisfaction. In addition to family and partner, friends (n=7) played an increasingly important role in the participants' lives.

Differences between employed and unemployed participants

The three persons who were unemployed post-intervention did not differ on demographic characteristics from persons who were employed (Table 1). At the individual level, however, each of them experienced problems in all three areas of occupational performance (work, self-care and leisure) at pre-intervention, and more than one problem in each area, compared to one out of eight employed participants. They showed a higher number of experienced problems on the COPM ($Z=-2.36$, $p=0.02$) and lower scores on the OPHI-II Occupational Settings scale ($Z=-2.16$, $p=0.03$), indicating a lessened perceived ability to interact in various environments related to work, home-life and social life (Table 5).

Post-intervention, both employed and unemployed persons showed improved occupational performance and satisfaction with performance to a level that met their needs, according to an increase in scores on COPM and OPHI-II and a decrease in the number of experienced problems. Unemployed persons showed similar levels post-intervention in occupational identity, occupational competence and occupational settings, compared to employed persons. The narratives of unemployed participants did not show a different (regressive) pattern.

Overall, unemployed persons started from a more complicated situation, and although they seem to catch up during the intervention regarding occupational performance they did not achieve employment within 1 year.

Table 5 Scores on the COPM and OPHI-II of persons who were employed and unemployed after the intervention

	Pre-intervention				**Post-intervention**			
	Employed persons (n=8)		Unemployed persons (n=3)		Employed persons (n=8)		Unemployed persons (n=3)	
	median	IQR	median	IQR	median	IQR	median	IQR
COPM								
Number of problems (n)[a]	24		23*		18		11	
Performance Subscale	4.8	(3.7)	4.8	(-)	7.2	(2.8)	6.2	(-)
Satisfaction Subscale	3.9	(4)	3.6	(-)	7.2	(3.8)	6.6	(-)
OPHI-II Scales:								
Occupational Identity	27.0	(7.0)	26	(-)	32.5	(11.2)	33	(-)
Occupational Competence	22.5	(6.0)	19	(-)	25.5	(6.5)	24	(-)
Occupational Settings	23.5	(3.5)	18*	(-)	28.0	(6.7)	30	(-)
OPHI-II Total score	73.5	(12.3)	64	(-)	86.0	(23.2)	82	(-)

[a] COPM Number of problems (n): total number of problems reported by subsamples
* Significant differences between employed and unemployed persons ($p<0.05$)

DISCUSSION

Young adults with physical disabilities who participated in a multidisciplinary intervention, converging rehabilitation and vocational services, showed improved occupational performance in all three areas of work, self-care and leisure, and were more satisfied with their performance. They showed improved occupational identity and occupational competence. During a relatively short period of 1 year, the study sample seems to show substantial changes: eight persons achieved suitable employment, three of them also made a transition to independent housing. In addition, most participants reported more active recreation and social leisure activities with friends post-intervention.

The intervention that was designed for young adults with physical disabilities has previously been shown to be feasible [17]. The present study provides a detailed description of the intervention and investigates changes in participants' occupational performance over time, addressing changes in in the areas of work, as well as self-care and leisure for both employed and unemployed persons.

Post-intervention, participants experienced less problems in work as well as in self-care, including functional mobility. These findings support the broad integrated approach of the intervention, and are consistent with others reporting that self-care independence and mobility are important factors for enabling

work participation among young adults with physical disabilities [7, 15]. The frequently reported problems in functional mobility correspond with other studies, and can be expected among young adults with physical disabilities [2-4, 13, 28]. The increased role of friends in their lives indicates increased independence and autonomy [29].

The ultimate goal of employment seemed to motivate participants to resolve problems in other areas which they previously disregarded or refused, e.g. ergonomic adjustments of their wheelchair, or coping with their disability. Thus, employment can be an important issue to address in the rehabilitation of young adults that may encourage them to improve their occupational performance in other areas.

The results of the intervention can be considered successful for all participants regarding their improvement in occupational performance. Those who did not achieve employment faced problems in all three areas of occupational performance pre-intervention, indicating a more complicated starting position. One person experiencing increased health problems when working, decided not to pursue employment any longer. All three unemployed persons were more satisfied with their occupational performance after the intervention. These findings might indicate that they solved problems in other areas of occupational performance (e.g. self-care) that may be a prerequisite for employment and need a longer period of time to achieve employment; on the other hand, they might have found other meaningful roles and activities (e.g. leisure) that contributed to increased acceptance of work disability.

A small decrease in the number of experienced problems for employed persons post-intervention, along with improved performance and satisfaction, might be explained by employed persons experiencing new problems that were associated with emerging roles and new activities, especially in work and active recreation.

The predictive value of narrative slopes for vocational outcomes reported in other studies [18, 26], in which progressive narratives were related to employment and regressive narratives to unemployment, was not confirmed in the present study sample. Possibly, the time span of one year was too short to expect substantial changes on this aspect.

Implications for practice

The combination of group sessions and individual coaching was appealing for young adults and seemed to contribute to improved occupational performance. The group sessions appeared to facilitate the process of change by contacts with peers and professionals; the individual coaching supported them to set personal goals for a productive and satisfying pattern of life.

The pre-intervention interviews contributed to increased appraisal of abilities and limitations, and provided valuable information about the needs of young adults and the problems they experience. Study participants preferred the OPHI-II interview because they found it easier to talk about meaningful roles and routines in their lives than to identify problems in daily activities, as is required in the COPM interview.

The present findings emphasize the need for a broad integrated approach for interventions aimed at improving work participation in this population, addressing not only work but also experienced problems in self-care and leisure. Young adults who achieve work participation may need continuing professional coaching to address new problems that arise with new roles and activities, concerning, for instance, transportation to work, changed daily routines in personal care, or more active leisure activities. Standardized assessments for monitoring and evaluation of goal achievement might be recommended as routine clinical practice for young adults.

Limitations of the study

The multi-diagnostic groups in the intervention resulted in a heterogeneous study sample. Although the main limitation of this study is the small sample size, we believe that with some caution the present findings may be generalized to other young adults with physical disabilities without severe intellectual disabilities in the Netherlands. Future research in a controlled study design should establish the effectiveness of the intervention.

Since work participation and vocational rehabilitation are influenced by socio-economic factors (such as social benefits, labour market) and organization of the health care system, generalization to other countries needs further study.

In conclusion, young adults with physical disabilities who participated in a 1-year multidisciplinary vocational rehabilitation intervention showed improved occupational performance in work, self-care and leisure, and were more satisfied with their performance. Persons who did not achieve employment faced problems in all three areas of occupational performance pre-intervention, indicating a more complicated starting situation.

The goal of employment and the broad integrated approach of the intervention seemed to motivate the participants to resolve problems in work, as well as self-care and leisure.

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Chapter 7

General discussion

MAIN FINDINGS

The main objective of this thesis was to design, evaluate and implement an evidence-based vocational rehabilitation intervention to improve work participation of young adults with physical disabilities caused by a chronic condition. In the first part of this thesis we identified available interventions to improve work participation, we explored the extent to which young adults with physical disabilities experience problems in work participation, and investigated an instrument used to evaluate work participation. The second part of this thesis focused on a new intervention to improve the work participation of young adults with physical disabilities.

First, we performed a systematic review of the literature to investigate the content and effectiveness of interventions to improve work participation of persons with a chronic physical condition. Results from the 25 included studies showed that overall, interventions aiming to improve the work participation of persons with a chronic physical condition seem to have a positive effect. However, the interventions varied widely regarding their content and delivery characteristics, and the quality of the evidence was rated as very low to low. The results were irrespective of the specific chronic condition, except for better effectiveness shown in persons with chronic pain or musculoskeletal disorders (Chapter 2).

Second, exploring the target group for the intervention, a study among young adults with cerebral palsy (CP) and average intelligence, showed that they are at risk for unfavorable development of work participation during their transition to adulthood. From age range 16-20 years to age range 20-24 years, the proportion of students decreased and the proportion of employed and unemployed persons increased. At age 20-24 years the employment rate of young adults with CP (49%) was lower and the unemployment rate was higher (17%), compared with

the general population of the same age. Of employed persons, 28% experienced situational or health barriers to employment (Chapter 3).

Third, we examined an instrument used to assess work limitations in persons with a chronic condition, in order to evaluate the intervention. It was shown that the modified Dutch-language version of the work limitations questionnaire (the WLQ-mdlv) was an intelligible, reliable and valid instrument to evaluate work limitations in employees with a chronic condition in the Netherlands (Chapter 4).

Next, the intervention 'At work?!' to improve the work participation of young adults with physical disabilities was designed and evaluated. This intervention, converging rehabilitation and vocational services, was implemented in an outpatient rehabilitation clinic for young adults. The cost of this intervention was reasonable, compared with the standard amount for an individual reintegration agreement. Preliminary results of the effectiveness were promising, with a higher proportion of participants being employed post-intervention, and maintaining this work participation at 2- and 3-year follow-up (Chapter 5). In addition, all participants showed improved occupational performance in work, as well as in self-care and leisure. Individuals that were unemployed post-intervention experienced problems in all three areas of occupational performance pre-intervention and, therefore, started from a more difficult situation. Although their occupational performance improved they did not achieve employment within one year. The actual goal to achieve employment, and the broad integrated approach of the intervention, seemed to contribute to improvement of the overall occupational performance of young adults (Chapter 6).

In this chapter, we discuss the results and main issues of this work within the context of the current literature. In addition, the methodological strengths and limitations of the studies are discussed, clinical implications are presented and some recommendations are made for future research.

VOCATIONAL REHABILITATION FOR PERSONS WITH A CHRONIC PHYSICAL CONDITION

Currently, government policies have shifted focus from disability towards a person's abilities, and emphasize active participation in society according to ability (1-3). There is increased interest in knowledge about interventions that improve work participation for persons with chronic physical conditions, in order to guide policy makers about which interventions should be implemented and financed by health insurance, and to enable health care professionals to provide evidence-based care (4-8).

Our review of the literature aimed to identify effective interventions to improve work participation of persons with physical chronic conditions (lasting ≥ 3 months), other than back disorders. For persons with a chronic condition, self-management support programs and an empowerment perspective have shown positive results, although their effectiveness regarding improved work participation has not yet been established (5, 9-11). In addition to our findings, other systematic reviews of the literature, addressing other study populations, found that early interventions, initiated in the first 6 weeks of absence from work, and work-place based interventions, promoting collaboration and coordination between different stakeholders (e.g. employees, employers and health care professionals) to implement work modifications, were effective in supporting return to work among employees on sick leave (6, 8). In young adults with physical disabilities, addressing these aspects in vocational rehabilitation interventions could contribute to sustained work participation and the prevention of health problems, work disability and/or job loss.

Health care insurers and consumers increasingly demand that interventions are evidence-based. Although vocational rehabilitation has basically shown to be cost-effective (12), evidence for the effectiveness of (specific) vocational rehabilitation interventions is limited and such interventions are generally excluded from health insurance compensation. Therefore, evidence for the effectiveness of interventions should be strengthened, especially for conditions other than chronic pain and musculoskeletal disorders. Currently, the overall success of interventions should encompass both a positive impact on work participation and cost-effectiveness (12, 13).

In young adults, we expect that the cost-effectiveness of vocational rehabilitation interventions will be positive, since the financial benefits of paid employment may have long-lasting effects on the reduction of disability pension. It is estimated that the financial gains for society for every young adult receiving *Wajong* disability benefit who achieves (part-time) employment will be about €17,000 per person/year (14).

TARGET GROUP FOR THE INTERVENTION

Work participation of young adults with physical disabilities is a highly relevant medical and societal issue. With the global economic crisis dating from 2007, young adults are facing increased difficulty to integrate into the labour market, resulting in high youth unemployment rates and many young people remaining in temporary, part-time, low-paid or unpaid jobs (13, 15). This economic context has

increased the challenge and difficulty for young adults with physical disabilities to find a job. For young adults with physical disabilities, our studies show that an integrated approach, including close cooperation between different stakeholders from health care and vocational services, is important for achieving suitable employment, and that the transition from school to work is a period with increased risks for unemployment (15-17). The vocational rehabilitation intervention 'At work?!' was designed to support these young adults to achieve work participation (shortly) after they have finished their education. Because the intervention includes a group program, the recruitment of participants is an important issue. Recruitment is facilitated by the vocational (non-conditional) approach of the intervention, allowing groups of young adults with various physical disabilities. However, although young adults with physical disabilities would welcome support in finding suitable employment (18, 19), recruitment of participants for the intervention appeared to be difficult and required much time and multiple strategies.

The intervention for young adults with physical disabilities primarily targets young adults receiving rehabilitation care and young adults receiving *Wajong* benefits. Our longitudinal study in young adults with cerebral palsy (CP) indicated that about 30% of the study sample may need support to improve their work participation, i.e. unemployed persons (17% of the study sample) and employed persons experiencing work limitations or barriers to work (14% of the study sample). Since the study sample consisted of a relatively well-functioning cohort of young adults with CP and average intelligence with high levels of gross motor functioning, these findings might underestimate the target group for the intervention. In the Netherlands, about 8.000 young adults aged ≤ 25 years with childhood-onset physical disabilities receive *Wajong* benefits (14). Although overall, an estimated 60-87% of young adults with *Wajong* benefits is partially capable of work, about 25% of those aged < 35 years is employed (2, 20). Unemployed young adults with *Wajong* benefits who are (partially) capable of work may want support to achieve employment. Moreover, not all young adults who are eligible for *Wajong* disability benefits actually apply for them.

Difficulty in reaching the target population can also be explained by the fact that different contexts and various stakeholders are involved, since young adults with physical disabilities are crossing the boundaries between pediatric and adult health care, as well as between care and social services, and education and work. Close collaboration between all relevant stakeholders may enhance recruitment of the participants. Also, the number of referred persons lagging behind expectations is a general area of concern in vocational rehabilitation, indicating that a

more general approach might be needed to address the referring (rehabilitation) physicians (12).

For the intervention 'At work?!', difficulties in recruitment were also related to the intervention characteristic to provide the support 'just-in-time', specifically addressing those young adults with physical disabilities who have (almost) finished their education and are available for the labour market. In addition to low recruitment, a high dropout rate of about 30% was observed in those who started the intervention, mainly due to the high burden of their chronic condition, pressure caused by finishing their education, or transitions in other domains (e.g. independent living) as well as a lower compliance that is typical for this age group (e.g. poor adherence, high no-show rates) (21). Recruitment of participants might be enhanced by a more flexible arrangement of the intervention, offering the group program as a part of (but not necessarily at the start of) the intervention, and should anticipate a certain percentage of drop-outs. Until now, participants have primarily been recruited via referring (rehabilitation) physicians and the local Dutch Employee Benefits Insurance Authority (UWV). In the future, recruitment strategies might include the young adults themselves, using increased possibilities of modern technology, internet and social media (e.g. websites, blogs, twitter, Facebook, LinkedIn). Such an approach is in line with a general self-management perspective.

DESIGN OF THE VOCATIONAL REHABILITATION INTERVENTION 'AT WORK?!'

The reviewed literature was used as a conceptual framework for the design of an intervention aiming to improve the work participation of young adults with physical disabilities entering the labour market. The intervention 'At work?!' had a generic (non-conditional) approach with a vocational focus. Based on the reviewed literature the following characteristics were included in the intervention: a multidisciplinary approach, intensive collaboration between the rehabilitation team and vocational professionals (e.g. job coach), and group treatment as well as individual coaching. In addition, elements of the concepts of empowerment and early intervention (for young adults: 'just in time') were incorporated (22). To enable young adults to achieve employment and adapt to new roles and routines, a relatively long duration of (at least) one year was combined with a low frequency (once a week, or less). The concept of occupational balance was used to encourage young adults to think about the consequences of work participation for activities in other domains (e.g. self-care and leisure) that they valued

or enjoyed (23). This broad perspective, addressing self-care independence and mobility to enable work participation for young adults with physical disabilities, is consistent with other studies (19, 24).

The intervention consisted of multiple components and incorporated a broad integrated perspective on occupational performance. Elements of Kielhofner's 'Model of Human Occupation' were used to apply this broad perspective and to emphasize the motivation for work (25). Recent studies have emphasized that motivation for work is an important factor to be assessed in young adults with disabilities to support them in finding employment (2, 26). Individuals who are motivated to work are more likely to show initiative to search for a job, to pursue guidance, and to overcome disappointments. In young adults, career choices are not always crystallized and motivation for work may change with increasing insight into their capabilities and limitations (27). The intervention 'At work?!' addressed motivation during two interviews that assisted participants to discover their own strengths and limitations, in order to support them to formulate realistic goals for work participation. Higher motivation, together with positive expectations regarding future work, are predictors of finding employment among young adults with disabilities (2).

Inclusion of job coaching in the intervention 'At work?!' was a major decision; moreover, the intensive collaboration between rehabilitation and vocational professionals in the intervention is the most innovative accomplishment of the intervention. The job coach is involved from the start and plays an important role in assessing work ability to assist young adults find suitable employment that is consistent with their physical abilities, education and interests, in order to achieve sustainable employment. The approach of the intervention, converging rehabilitation and vocational services with group and individual sessions alongside job coaching, was commented upon as both novel and refreshing (28). Although studies in other countries have reported a multidisciplinary approach including professionals from health care and vocational specialists (29-32), in the Netherlands this combination is not standard and is complex, since vocational services are not covered by health care insurance. Participants who had previously been (unsuccessfully) supported by health care or vocational services, evaluated the integration of expertise from both domains, as well as the close collaboration between the professionals, as the most important characteristic of the intervention. However, since both professionals are financed from different sources, this aspect has hampered implementation of the intervention in other centers.

IMPLEMENTATION OF THE INTERVENTION

Successful implementation of effective interventions in the field of vocational rehabilitation is a major challenge, because many stakeholders are involved and interventions are often complex, consisting of multiple components and addressing different aspects of both the person and the (work) environment (5, 6, 33). The intervention 'At work?!' has been provided for seven years, with two new groups of 6-10 young adults starting each year in the outpatient clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre in Rotterdam. To achieve implementation of the intervention we used multiple strategies addressing professionals, the intervention and collaboration between different professionals, that were tailored to the specific setting and target group (34). Providers were involved in the design of the intervention to fit the intervention to the context, a joint conference increased knowledge on the theoretical assumptions underlying the intervention, and close cooperation between researcher, occupational therapist and job coach contributed to shared responsibility for the organization of the intervention. In addition, collaboration with the local Dutch Employee Benefits Insurance Authority (UWV) was initiated at the very beginning. After the start of the intervention, decreasing responsibilities of the researcher together with increasing responsibilities of the providers for new intervention groups contributed to implementation. Since 2011, the intervention has also been implemented in rehabilitation centers in Leiden and Amsterdam. In another rehabilitation center implementation was not successful, because a different intervention targeting young adults with traumatic brain injury was preferred. The intervention 'At work?!' is available through the Dutch network to improve transitional rehabilitation care for young adults (TransitieNet). A 'train-the-trainers' course facilitates implementation of the intervention in other contexts, offering support to new providers and initiating collaboration between health care and vocational professionals. Dutch language publications on the intervention aim to contribute to further implementation in the Netherlands (35, 36).

Implementation of interventions is often hampered by poor quality (e.g. unclear, or incomplete) description of the interventions in publications, hindering professionals to implement interventions in practice, and discouraging researchers to replicate or build on research findings (37). To improve the quality of reporting on interventions, a 12 item Template for Intervention Description and Replication (TIDieR) checklist was recently developed (37). Post-hoc consideration of our published description of the intervention (Chapter 6) showed that the description included all 12 items of the TIDieR checklist. However, based on the explanation of items in the checklist we could further clarify the description of some items to

better facilitate implementation of the intervention by other professionals and in other contexts.

Many different (and changing) professionals in vocational rehabilitation, and changing regulations and financial structures, may also be barriers for implementation. Introduction of the Participation Act in the Netherlands in 2015, will shift responsibility from central government to the local authorities, and will present a major challenge (38, 39). The municipalities will become responsible for the support and services to persons with disabilities who are (partially) capable to work, but who need assistance to integrate into the labour market. From 2015 onwards, only young disabled persons who are fully and permanently incapacitated to work will be eligible for the Invalidity Insurance (Young Disabled Persons) Act ('*Wajong*'). The (national) Dutch Employee Benefits Insurance Authority (UWV) remains responsible for the re-integration of those who already received *Wajong*-benefits prior to 2015 (38, 39). These changes will have a substantial impact on the financing of the intervention and will affect further implementation. The future challenge is to initiate collaboration with municipalities to provide the intervention in other contexts. Since municipalities will be responsible for disability benefits and for providing support to young adults, (cost-effective) support programs with a positive outcome for work participation of young adults with disabilities will produce a positive return on investment, because a reduction in disability benefits decreases the financial burden on the municipality.

METHODOLOGICAL CONSIDERATIONS

Strengths and limitations of the studies

A strength of the study exploring the development of work participation in young adults with cerebral palsy is its longitudinal design, following the participants over a 4-year period during the transition to adulthood, collecting data on work participation and other domains.

The focus of the systematic review of the literature, identifying generic interventions to improve the work participation of persons with a chronic condition (instead of focusing on a specific diagnosis), also yielded important information.

A main strength of this thesis is the design, evaluation (addressing both feasibility and preliminary effectiveness) and implementation of a new evidence-based intervention. A focus on implementation from the start of the study, involving different stakeholders in the process, contributed to successful implementation of the intervention at the outpatient clinic for young adults at Erasmus MC and Rijndam Rehabilitation Centre in Rotterdam. This process also served to prepare

for implementation of the intervention in other centers in the Netherlands. In this way, the present research has contributed to improving actual practice.

In order to evaluate the intervention we aimed to include 12-16 participants in the feasibility study. The study sample, although small, satisfied the present study aims to explore changes in participants' work participation and occupational performance over time. Despite the small sample size, the multi-diagnostic groups in the intervention resulted in a heterogeneous study sample, which corresponds with the prevalence of chronic conditions among young adults and reflects the target population of the intervention.

Some methodological limitations also need to be addressed. In documenting the development of work participation in young adults with cerebral palsy, a longer follow-up period (e.g. up to age 26-30 years) might have provided a more comprehensive description of the transition to work, since over 30% of the sample was still studying at the age of 20-24 years.

In our systematic review of the literature, the different periods of follow-up in the included studies hampered comparison of the effectiveness of the interventions and may have led to either underestimation or overestimation of the effectiveness of some of the interventions.

The main limitations of the feasibility study, evaluating the intervention 'At work?!' to improve work participation of young adults with physical disabilities, are the lack of a control group and the small sample size. Since the intervention was implemented in the outpatient clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre that was in an early stage of establishment at the time of our study, the recruitment of participants had to be initiated and further explored. Evaluation of the intervention in a controlled trial was not yet feasible and, therefore, we performed a feasibility study with a pre-post intervention design. Since this study showed that providing the intervention is feasible, a multicenter controlled study with a larger study sample is currently taking place to further investigate the effectiveness of the intervention (Netherlands Trial Register number NTR4145).

The intervention was provided by an occupational therapist and a job coach, both of whom lacked experience in the treatment and coaching of, specifically, young adults. However, since the participants evaluated the coaching and support positively, we assume that the lack of experience of the professionals with this specific target population did not adversely affect the present results. The close cooperation between the occupational therapist and the job coach may have contributed positively to the outcomes of the intervention.

With regard to the statistical analysis, because the number of analyses performed to evaluate the feasibility of the intervention was large in relation to the small sample size, the results need to be interpreted with some caution.

Finally, generalizability of the results of the feasibility study and the longitudinal study exploring the development of work participation in young adults with cerebral palsy to other countries might be limited because work participation is influenced by legislation and the labour market in a country as well as by socio-economic factors, such as health insurance and social benefits. However, the approach of the intervention 'At work?!' can be applied in other countries and can be used as framework for further research on the work participation of young adults with physical disabilities.

Outcome measures of work participation

We used generic measures to measure (changes in) work participation including the person and the (work) environment, and addressed both quantitative and qualitative aspects of work participation (40-43). Since balancing work with other activities is reported to be a major problem for employed persons with a chronic physical condition, assessments included work and activities in other domains (42, 44). In our feasibility study the primary outcome measure was work participation; in addition, work ability and work limitations, as well as occupational performance, were measured.

Work participation

Work participation pre- and post-intervention was measured using the PROductivity and DISease Questionnaire (PRODISQ), module B (45); however, in 2013, the PRODISQ was replaced by the Productivity Cost Questionnaire (iPCQ) (46). The job coach provided post-intervention data on work participation, as well as data on the 2- and 3-year follow-up. Because we included both paid and unpaid employment in work participation, we reported the number of persons with unpaid employment separately, to prevent overestimation of the employment rates in our results. Since work participation was measured annually, at previously determined moments in time, we did not capture work participation in the periods in between. However, by using the data from the job coach, we are convinced that all participants were correctly classified.

Use of the definition of Statistics Netherlands, i.e. working ≥ 12 hours/week, implies that we categorized those who performed a substantial amount of work during the week as 'employed'. This enabled comparison of the employment rate of participants with the employment rate of the general Dutch population of the same age. However, use of this definition may impede comparison of our results

with other countries in which 'employed' is often defined as any work for pay or profit during the reference week, even for as little as 1 hour, according to the definition provided by the International Labour Organization (47).

Work ability and work limitations

Work ability and work limitations of young adults who were employed after the intervention were measured to determine whether they had achieved suitable employment. For this, we used the Work Ability Index (WAI) and a modified Dutch-language version of the Work Limitations Questionnaire (WLQ-mdlv); these are two reliable (self-reporting) questionnaires suitable for working persons (48-51).

The WLQ has been used in adults with various chronic conditions and in healthy employees aged 18-65 years (52), but not yet in a population of young adults and not yet in the Netherlands. In interpreting the present WLQ-scores, reference values for healthy employees in the Netherlands were lacking and are not yet available (53).

The WAI has been used in young adults (54-56). We classified the work ability of the participants in the intervention using the general reference limits for WAI scores. However, this might have resulted in a slight overestimation of work ability, because the recommended reference limits may be too low for young employees and might need some adjustment (55). Therefore, the interpretation of the WAI scores should be reconsidered in a larger controlled study, to better establish the effectiveness of the intervention.

Occupational performance

The Occupational Performance History Interview (OPHI-II) and the Canadian Occupational Performance Measure (COPM) were used to measure occupational performance. The OPHI-II can be used among adolescents and has shown to be a valid measure across age, diagnosis, culture and language (57). The semi-structured interview is based on the 'Model of Human Occupation' and is considered a useful tool in work assessment; in addition the life history narrative is reported to have predictive value for vocational outcomes (25, 58-61).

In a semi-structured interview, the COPM captures actual occupational performance, as well as satisfaction with performance and the importance of (work) activities and roles for an individual. The COPM includes qualitative aspects of occupational performance and has been used among young adults (18, 62). Although neither of these measures was designed for work-specific assessments, both measures are useful to generate goals and to inform interventions. As compared to the OPHI-II, the COPM is easier to use in clinical practice and takes less time. However, the OPHI-II interview provided additional valuable informa-

tion to guide the intervention, e.g. about successes and failures in previous work experiences, support received in finding and maintaining employment, and about disappointments and expectations towards professionals. Some participants mentioned that the OPHI-interview was one of the most valuable and interesting elements of the intervention, because the interview encouraged them to think about their (future) work situation, and patterns in activities and participation.

CLINICAL IMPLICATIONS

I Availability of a vocational rehabilitation intervention for young adults

The present thesis provided professionals in clinical practice with a vocational rehabilitation intervention to support young adults with physical disabilities to achieve suitable employment. The intervention 'At work?!' has shown to be feasible and can be implemented in other rehabilitation centers in the Netherlands. New providers are supported by a training to understand the theoretical assumptions underlying the intervention and to initiate collaboration between the rehabilitation team and job coaches. As a result of new regulations planned for 2015, the intervention can be provided in other contexts in collaboration with local municipalities.

The intervention can be further improved by enhancing collaboration with the employer, and having a more flexible arrangement of the group program (e.g. not necessarily at the start of the intervention). On the longer term, the use of modern technology and social media can contribute to further improvement (e.g. efficiency) and innovation of the group program.

II Vocational rehabilitation for young adults needs a broad integrated approach

Based on our findings, vocational interventions for young adults with physical disabilities should use a broad, integrated approach and address work, as well as activities in other areas, such as self-care and leisure. We learned that the goal of work participation can motivate young adults to address issues in other domains, that may serve as a prerequisite to achieve work participation. Pre-intervention assessment serves to enable the participant and the professional to determine realistic goals together to guide the intervention. In addition, post-intervention assessments are included to evaluate if the participant's goals are achieved. However, in young adults, primary aim of post intervention assessment is to identify new issues that are associated with emerging roles and new activities, in work as well as self-care and leisure.

III To achieve suitable employment for young adults, the focus should be on work abilities

Suitable employment that is consistent with the participant's physical abilities and level of education, can prevent or reduce future health problems or work disability and is important for sustained work participation in young adults with physical disabilities. A focus on work abilities in the assessments and interventions, aiming to enhance a person's insight into their abilities, addressing motivation and offering training to improve (work) abilities, will contribute to achieving suitable employment and is consistent with current policy.

IV A smooth transition from school to work by enhanced collaboration with education

Since young adults with physical disabilities are at increased risk for unemployment in the transition period from school to work, this is a vital period to provide support to find suitable employment. Enhanced collaboration with educational institutions may contribute to a smooth transition from school to work for those young adults who need support. In addition, enhanced collaboration can contribute to careful identification of the most adequate support, e.g. the intervention 'At work?!', rehabilitation services (e.g. occupational or physical therapy), vocational services (e.g. job coaching) or a specialized temporary employment agency (such as 'Emma at work'). In addition, 'suitable education' that prepares the young adults for a job that is consistent with their physical abilities could enhance suitable employment. The latter aspect could be addressed by rehabilitation professionals or vocational counsellors when young adults choose vocational education or internships.

RECOMMENDATIONS FOR FUTURE RESEARCH

I Evidence for effectiveness of the intervention 'At work?!'

Erasmus University Medical Centre and Rotterdam University of Applied Sciences are conducting a multicenter controlled study in a larger study sample to provide additional evidence for the effectiveness of the intervention 'At work?!' that we developed and evaluated. We recommend to focus evaluation of the effectiveness on:

- achievement of suitable employment using measures addressing work ability, work limitations, and/or perceived health. In the interpretation of scores, adjustment of reference limits might be needed for young (working) adults, as was recommended for the Work Ability Index.

- changes in occupational performance of participants, including not only work but also self-care and leisure, using the Occupational Performance History Interview (OPHI-II) and the Canadian Occupational Performance Measure (COPM) pre- and post-intervention.
- cost-effectiveness, including return on investment, since for young adults the financial benefits of paid employment may have long-lasting effects, reducing their disability benefits and decreasing the financial burden on society.

II Longitudinal studies to document the development of work participation in young adults

With the increasing number of young adults with a chronic condition in the Netherlands future research addressing interventions aiming to improve participation and autonomy of young adults with disabilities, contributing to a successful transition to adulthood, is highly relevant. Our studies among young adults with cerebral palsy and young adults with various physical disabilities participating in the intervention, provided insight into the transition from school to work. Longitudinal studies following these young adults up to the age of 30 years, evaluating their work participation every year, might provide increased insight into the development of suitable and sustainable work participation and the vocational careers of young adults with physical disabilities.

III Strengthening the evidence for effectiveness of vocational rehabilitation interventions

Since evidence for the effectiveness of (specific) vocational rehabilitation interventions is limited, further research is needed on interventions that aim to improve and sustain work participation in persons with a chronic physical condition, especially for chronic conditions other than chronic pain and musculoskeletal disorders. Important aspects in strengthening the evidence are:

- interventions should be clearly described to encourage researchers to build on previous studies and enable clinicians to apply the intervention in practice;
- outcome measures for work participation should be similar or comparable across studies to improve comparison of results and enable the performance of meta-analysis;
- follow-up should include long-term follow-up and the report of outcomes at different follow-up moments to enable evaluation of sustainable employment.

IV Implementation of research findings in clinical practice

To improve the use of research findings in clinical practice, and to enhance evidence-based care, studies should include strategies for implementation of interventions or evidence in clinical practice. Researchers can make an important contribution by addressing implementation from the start and by collaborating with professionals (e.g. therapists) in clinical practice. With the establishment of research centers and the appointment of applied research professors in 2001, the universities of Applied Sciences in the Netherlands can contribute to the implementation of research findings in health care practice, specifically addressing allied health care professionals (e.g. occupational therapists, speech-language therapists, physical therapists) and nurses.

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SUMMARY

This thesis addresses the work participation of young adults with physical disabilities caused by a chronic condition. Research has mainly focussed on return to work of adults with a chronic physical condition, while less is known about young adults that were diagnosed before they were entering the labour market. With increasing numbers of young people with a chronic physical condition living into adulthood, knowledge about the development of work participation in these young adults and the support they need to achieve suitable employment is highly relevant. Interventions to improve work participation of young adults with physical disabilities were lacking. The main objective of this thesis was to design and evaluate a vocational rehabilitation intervention to improve the work participation of young adults with physical disabilities.

Chapter 1 provides a general introduction to chronic physical conditions, work participation of (young) people with a chronic physical condition, and interventions to improve the work participation of young adults with a chronic physical condition and concludes with the research questions for this thesis and an outline of this thesis:

1. What evidence is available regarding effective interventions to improve the work participation of persons with a chronic physical condition? (Chapter 2)
2. How does work participation develop in young adults with cerebral palsy during their transition to adulthood? (Chapter 3)
3. Is the modified Dutch-language version of the work limitations questionnaire an intelligible, reliable and valid instrument to assess work limitations among working persons with a chronic condition in the Netherlands? (Chapter 4)
4. Is it feasible to implement a new vocational rehabilitation intervention to improve the work participation of young adults with physical disabilities caused by a chronic condition in an outpatient clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre, Rotterdam? (Chapter 5 and 6)

Chapter 2 presents a systematic review of the literature, evaluating the characteristics and effectiveness of intervention aiming to improve work participation of adults with a chronic physical condition. After a systematic electronic search in medical databases 25 studies were included and assessed for their methodological quality. The strength of the body of evidence was assessed using the Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE). The results showed that interventions addressing work participation varied widely regarding delivery characteristics and content. Overall, inclusion of group treatment, a multidisciplinary approach and a high frequency, often combined with a short duration (< 8 weeks), were more often used. We found evidence for effectiveness of interventions on work participation, but the quality of the evidence was rated low regarding work productivity and very low regarding work status and work attitude.

Chapter 3 describes the development of work participation in a study sample of 74 young adults with cerebral palsy (CP) of average intelligence over a 4-year period, during their transition to adulthood. In an observational longitudinal cohort study, work participation in 3 categories (employed, unemployed, studying) was assessed at age 16-20 years, 2-year and 4-year follow-ups. At 4-year follow-up, associations of work participation with demographic and clinical characteristics were examined, and work limitations and barriers among employed persons.

From age 16-20 years to age 20-24 years the proportion students decreased (from 85% to 34%) and the proportion of employed as well as the proportion of unemployed young adults increased (from 12% to 49% and 3% to 17%, respectively). Aged 20-24 years, the employment rate of young adults with CP was lower and the unemployment rate higher, than that of the general population of the same age. A lower level of gross motor function and younger age were associated with unemployment. Employed persons experienced few work limitations; 28% experienced situational or health barriers for work.

Chapter 4 describes the intelligibility and psychometric properties of the modified Dutch language version of the Work Limitations Questionnaire (WLQ-mdlv). We assessed the intelligibility, internal consistency, test-retest reliability and external construct validity of the WLQ-mdlv in a study sample of 125 employed patients with a chronic physical condition who completed the WLQ-mdlv, the Work Ability Index (WAI) and the Medical Outcomes Study 36-item Short-Form health survey (SF-36). The reliability and external construct validity of the four WLQ-mdlv scales and index were confirmed in a miscellaneous sample of Dutch

patients with a chronic condition. The WLQ-mdlv showed to be an intelligible, reliable and valid instrument for evaluating work limitations in employees with a chronic condition in the Netherlands.

Chapter 5 evaluates the feasibility of a new 1-year multidisciplinary intervention aiming to improve the work participation of young adults with physical disabilities. The intervention converged rehabilitation and vocational services and combined a group program with individual assessments and coaching. In a pre-post intervention design, we assessed implementation and costs as well as preliminary effectiveness on work participation, including work ability, work limitations and occupational performance. In addition, work participation after 2 and 3 years was assessed.

Twelve young adults with physical disabilities (median age 22 years and 6 months) participated in the intervention and the feasibility study. The intervention was implemented in the outpatient rehabilitation clinic for young adults of Erasmus MC and Rijndam Rehabilitation Centre Rotterdam. Median cost per participant for 1 year was €3128 (equivalent of 72 hours). Post-intervention, and at 2- and 3-years follow-up, a significantly higher proportion of participants were employed, with the ratio of those in paid to unpaid employment being 4:4, 5:3 and 7:1 respectively. Employed participants showed moderate work ability and experienced work limitations during approximately 20-33% of the time. Employed participants seemed to have achieved suitable and continuous employment.

Chapter 6 describes into more detail the changes over time in occupational performance of participants of the 1-year multidisciplinary vocational rehabilitation intervention, as measured with the Canadian Occupational Performance Measure (COPM) and the Occupational Performance History Interview (OPHI-II), as well as differences between employed and unemployed persons.

Post-intervention, participants experienced fewer problems and showed improved occupational performance in work, as well as self-care and leisure, and improved satisfaction with performance. Participants also showed improved occupational identity and occupational competence. Participants who did not achieve employment experienced problems in all three areas of occupational performance at the start. Although they seemed to catch up during the intervention, they did not achieve employment within one year. The goal of employment and the broad integrated approach of the intervention seemed to motivate participants to resolve problems in work, as well as self-care and leisure.

Finally, **chapter 7** discusses the main findings of this thesis within the context of the current literature, as well as the strengths and limitations of the studies and outcome measures of work participation. We conclude with clinical implications and recommendations for future research.

SAMENVATTING

Dit proefschrift beschrijft de arbeidsparticipatie van jongvolwassenen met lichamelijke beperkingen als gevolg van een chronische aandoening. Onderzoek heeft zich met name gericht op terugkeer naar werk van volwassenen met een chronische aandoening, en kennis over de arbeidsparticipatie van jongvolwassenen die gediagnosticeerd zijn voordat zij de arbeidsmarkt betreden is beperkt. Een toenemend aantal jongvolwassenen met een chronische fysieke aandoening bereikt een volwassen leeftijd, en kennis over de ontwikkeling van arbeidsparticipatie bij deze jongvolwassenen en de ondersteuning die zij nodig hebben om passend werk te vinden is zeer relevant. Er zijn echter geen interventies bekend om de arbeidsparticipatie te verbeteren van jongvolwassenen met lichamelijke beperkingen. Het doel van dit proefschrift is het ontwikkelen en evalueren van een nieuwe interventie om de arbeidsparticipatie te verbeteren van jongvolwassenen met lichamelijke beperkingen als gevolg van een chronische aandoening.

Hoofdstuk 1 geeft een inleidende beschrijving van chronische fysieke aandoeningen, arbeidsparticipatie van (jong)volwassenen met een chronische fysieke aandoening en interventies om de arbeidsparticipatie van jongvolwassenen met een chronische fysieke aandoening te verbeteren. Dit hoofdstuk besluit met de onderzoeksvragen en de opbouw van dit proefschrift:

1. Wat is het beschikbare bewijs met betrekking tot effectieve interventies om de arbeidsparticipatie te verbeteren van mensen met een chronische fysieke aandoening? (Hoofdstuk 2)
2. Hoe ontwikkelt de arbeidsparticipatie van jongvolwassenen met cerebrale parese zich gedurende de transitie naar volwassenheid? (Hoofdstuk 3)
3. Is de aangepaste Nederlandstalige versie van de 'Vragenlijst beperkingen werk' een duidelijk, betrouwbaar en valide instrument om beperkingen in werk te onderzoeken bij mensen met een chronische fysieke aandoening in Nederland? (Hoofdstuk 4)

4. Is het haalbaar om een nieuwe interventie te implementeren om de arbeidsparticipatie te verbeteren van jongvolwassenen met lichamelijke beperkingen als gevolg van een chronische aandoening in een polikliniek voor jongvolwassenen van Erasmus MC en Rijndam revalidatiecentrum in Rotterdam? (Hoofdstukken 5 en 6).

Hoofdstuk 2 beschrijft een systematische literatuurstudie naar de kenmerken en effectiviteit van interventies gericht op het verbeteren van de arbeidsparticipatie van mensen met een chronische fysieke aandoening. Na een systematische elektronische zoektocht in medische databases zijn 25 studies geïncludeerd en beoordeeld op methodologische kwaliteit. De bewijskracht is beoordeeld met behulp van de 'Grades of Recommendation, Assessment, Development and Evaluation Working Group' (GRADE). De resultaten laten zien dat interventies om de arbeidsparticipatie te verbeteren sterk uiteenlopen met betrekking tot inhoud en organisatie. In het algemeen worden groepsbehandeling, een multidisciplinaire benadering en een hoge frequentie, vaak gedurende een korte periode (< 8 weken) meer toegepast. Er is bewijs voor de effectiviteit van interventies op arbeidsparticipatie, maar de kwaliteit van het bewijs is beoordeeld als laag voor arbeidsproductiviteit en zeer laag voor werkstatus en werkhouding.

Hoofdstuk 3 beschrijft de ontwikkeling van arbeidsparticipatie in een steekproef van 74 jongvolwassenen met cerebrale parese (CP) met normale intelligentie gedurende een periode van vier jaar, tijdens hun transitie naar volwassenheid. In een longitudinaal cohortonderzoek is arbeidsparticipatie bepaald in één van drie categorieën (werkend, werkloos, studerend) op een leeftijd van 16-20 jaar, twee jaar later en vier jaar later. Bij de 4-jaar follow-up zijn associaties van arbeidsparticipatie met demografische en klinische kenmerken nagegaan, en de beperkingen in werk en barrières ten aanzien van werk die werkende personen ervaren. Van een leeftijd van 16-20 jaar tot 20-24 jaar nam het aandeel studenten af (van 85% naar 34%) en nam zowel het aandeel werkende als het aandeel werkloze jongvolwassenen toe (respectievelijk van 12% naar 49% en van 3% naar 17%). Op een leeftijd van 20-24 jaar was een kleiner deel van de jongvolwassenen met CP werkzaam en een groter deel werkloos, in vergelijking met de algemene bevolking van dezelfde leeftijd. Een lager niveau van algemeen motorisch functioneren en een lagere leeftijd waren geassocieerd met werkloosheid. Werkende personen ondervonden weinig beperkingen in werk; 28% ondervond (arbeids) barrières met betrekking tot de omgeving of hun gezondheid.

Hoofdstuk 4 beschrijft de duidelijkheid en de psychometrische eigenschappen van de 'vragenlijst beperkingen werk', de aangepaste Nederlandstalige versie van de 'Work Limitations Questionnaire' (WLQ-mdlv). De duidelijkheid, interne consistentie, test-hertest betrouwbaarheid en externe constructvaliditeit van de WLQ-mdlv zijn onderzocht in 125 werkende volwassen patiënten met een chronische fysieke aandoening. Deze 125 patiënten hebben de WLQ-mdlv ingevuld, de vragenlijst werkvermogen (WAI) en een vragenlijst naar de ervaren gezondheid (Medical Outcomes Study 36-item short-form health survey of SF-36). De betrouwbaarheid en externe constructvaliditeit van de vier schalen en de index van de WLQ-mdlv zijn bevestigd in een steekproef van Nederlandse patiënten met diverse chronische aandoeningen. De WLQ-mdlv is een duidelijk, betrouwbaar en valide instrument om beperkingen in werk te evalueren bij werknemers met een chronische fysieke aandoening in Nederland.

Hoofdstuk 5 evalueert de haalbaarheid van een nieuwe multidisciplinaire interventie om de arbeidsparticipatie van jongvolwassenen met lichamelijke beperkingen te verbeteren. De interventie 'Aan het werk?!' integreert revalidatie en re-integratie en combineert een groepsprogramma met individuele assessments en coaching gedurende één jaar. In een pre-post interventie design zijn de implementatie onderzocht, inclusief de kosten, en de voorlopige effectiviteit op arbeidsparticipatie, inclusief werkvermogen, beperkingen in werk en dagelijks handelen. Tevens is de arbeidsparticipatie na twee en drie jaar bepaald.

Twaalf jongvolwassenen met lichamelijke beperkingen (mediaan leeftijd 22 jaar en 6 maanden) namen deel aan de interventie en de haalbaarheidsstudie. De interventie is geïmplementeerd in een polikliniek jongvolwassenen van Erasmus MC en Rijndam revalidatie centrum in Rotterdam. Kosten (mediaan) per deelnemer voor één jaar bedroegen €3128,- (equivalent van 72 (arbeids)uren). Post-interventie en bij 2- en 3-jaar follow-up participeerde een significant groter deel van de deelnemers in werk, met een ratio van betaald versus onbetaald werk van respectievelijk 4:4, 5:3 en 7:1. Het werkvermogen van werkende deelnemers was matig en zij ondervonden ongeveer 20-33% van de tijd beperkingen in werk. Werkende deelnemers leken duurzaam en passend werk gevonden te hebben.

Hoofdstuk 6 biedt een meer gedetailleerde beschrijving van de veranderingen in het dagelijks handelen van de deelnemers van de interventie 'Aan het werk?!' in de tijd, zoals gemeten met de Canadian Occupational Performance Measure (COPM) en het Occupational Performance History Interview (OPHI-II). Tevens zijn de verschillen tussen deelnemers met en zonder werk na de interventie nagegaan.

Na de interventie rapporteerden deelnemers minder problemen in dagelijkse handelingen en een verbetering in de uitvoering van dagelijkse handelingen, zowel met betrekking tot werk, als met betrekking tot zelfzorg en vrije tijd; ook waren deelnemers meer tevreden over de uitvoering van dagelijkse handelingen. Daarnaast was de handelingsidentiteit en handelingscompetentie van deelnemers verbeterd. Deelnemers die niet participeerden in werk rapporteerden bij de start problemen in alle drie de handelingsgebieden. Hoewel hun dagelijks handelen was verbeterd, bereikten zij geen arbeidsparticipatie binnen de periode van één jaar. Het doel werk te vinden en de brede geïntegreerde benadering van de interventie leken de deelnemers te motiveren om niet alleen problemen met werk, maar ook met zelfzorg en vrije tijd op te lossen.

Tenslotte beschrijft **hoofdstuk 7** de belangrijkste resultaten van het gehele onderzoek in relatie tot de huidige literatuur, alsmede sterke kanten en beperkingen van de studies en uitkomstmaten van arbeidsparticipatie. We sluiten af met implicaties voor de praktijk en aanbevelingen voor toekomstig onderzoek.

DANKWOORD

Dit promotieonderzoek was leerzaam, uitdagend en moeilijk te plannen. In combinatie met een baan als (hoofd)docent was het hard werken en goed organiseren. Maar het was ook leuk – om onderzoek te doen, te blijven leren, samen te werken met nieuwe mensen en successen te vieren. Ik waardeer het dan ook zeer dat ik deze kans heb gekregen, met steun van de stimuleringsregeling Promoveren in het hbo.

Mijn studieroute loopt van hbo-ergotherapie naar wo-bewegingswetenschappen en vandaar naar dit promotieonderzoek. Tijdens die route is de typemachine verruild voor een computer en vervolgens een laptop met draadloos internet. Hoewel de technologische ontwikkelingen hebben bijgedragen aan het eindresultaat, zijn alle personen die bij het onderzoek betrokken waren van veel groter belang geweest.

Omdat het onmogelijk is iedereen die heeft bijgedragen aan dit proefschrift met name te noemen wil ik ALLE collega´s, deelnemers, studenten, vrienden en familie bedanken die direct of indirect een bijdrage hebben geleverd door hun inspiratie, steun, vertrouwen, kennis, aanmoediging, interesse, nieuwsgierigheid, relativeringsvermogen of gevoel voor humor. Mede dankzij jullie is de eindstreep bereikt.

Vooral wil ik de jongvolwassenen bedanken die hebben deelgenomen aan de interventie. Ik heb jullie vertrouwen, inzet en doorzettingsvermogen bij het *TraJect* naar een baan met plezier en bewondering gevolgd. Dankzij de betrokkenheid en het enthousiasme van Monique Floothuis en Natascha van Schaardenburgh is de combinatie van revalidatie en re-integratie in de interventie gerealiseerd en start sinds 2007 tweemaal per jaar een nieuwe groep jongvolwassenen met de interventie. De congressen in Chili en Japan waren bijzondere hoogtepunten in onze toch al zo leuke samenwerking!

In het bijzonder wil ik Marij Roebroeck en Harald Miedema bedanken: zonder jullie begeleiding, deskundigheid, steun en vertrouwen had dit promotieonderzoek naar het verbeteren van de arbeidsparticipatie van jongvolwassenen met licha-

melijke beperkingen niet plaats kunnen vinden. De leerzame en inspirerende discussies en jullie zorgvuldige, deskundige en kritische commentaren op de onderzoeksopzet, analyses en concepten en hebben in belangrijke mate bijgedragen aan het eindresultaat. Ik heb veel van jullie geleerd en ook altijd met veel plezier met jullie samengewerkt, en hoop die samenwerking in de toekomst dan ook voort te kunnen zetten! Mijn promotor Prof. Henk Stam wil ik bedanken voor zijn constructieve commentaren op concepten, zijn heldere argumentatie en zijn focus op de hoofdlijnen.



Alle (oud)collega's van het docententeam ergotherapie, het Kenniscentrum Zorginnovatie en de revalidatiegeneeskunde van het Erasmus MC wil ik bedanken voor de samenwerking en hun interesse, steun, adviezen, discussies en kritische commentaren, en in het bijzonder:

- Kim de Vries en Jan van Veen die als onderwijsmanagers de voorwaarden hebben gecreëerd om dit promotieonderzoek uit te voeren en af te ronden door mijn (onderwijs)taken aan te passen. Bedankt voor jullie steun en vertrouwen!
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ABOUT THE AUTHOR

Joan Verhoef was born on April 15, 1961 in Amsterdam, the Netherlands. After graduating from secondary school (gymnasium B) at the Marnix College in Ede in 1979, she completed a one-year secretarial course (Institute Schoevers, Arnhem). In 1980, she started studying occupational therapy in Hoensbroek and she obtained her Bachelor degree in 1984 (BScOT). She worked as an occupational therapist in nursing homes in Rosmalen and Roermond and in the Leiden University Medical Center (1988-1996).

In 1991, she started a Master of Science in Human Movement Sciences at the VU University in Amsterdam, with a major on 'History and theory of movement sciences'. She obtained her Master degree in 1997 with a thesis on the 'Model of Human Occupation' of Kielhofner.

In 1995, she started working as a lecturer occupational therapy at the Rotterdam University of Applied Sciences. From 2001, she combined working as a lecturer with working as a researcher at the Research Centre Innovations in Care of Rotterdam University of Applied Sciences.

In September 2006, she started with the PhD project resulting in this thesis at the Department of Rehabilitation Medicine of Erasmus University Medical Center, Rotterdam.

Currently, she is working as a principal lecturer 'Evidence-based care' at the Rotterdam University of Applied Sciences, School of Health Care Studies (occupational therapy) and Research Centre Innovations in Care.

LIST OF PUBLICATIONS

(Submitted for publication)

Verhoef JAC, Bal MI, Roelofs PDDM, Borghouts JAJ, Roebroeck ME, Miedema HS. Effectiveness of interventions to improve work participation in adults with chronic physical conditions: a systematic review. (*Submitted for publication*)

2014

Verhoef JAC, Bramsen I, Miedema HS, Stam HJ, Roebroeck ME. Development of work participation in young adults with cerebral palsy: A longitudinal study. J Rehabil Med. 2014;46(7):648-55.

Verhoef JAC, Roebroeck ME, van Schaardenburgh N, Floothuis MC, Miedema HS. Improved occupational performance of young adults with a physical disability after a vocational rehabilitation intervention. J Occup Rehabil. 2014;24(1):42-51.

2013

Verhoef JAC, Miedema HS, Van Meeteren J, Stam HJ, Roebroeck ME. A new intervention to improve work participation of young adults with physical disabilities: a feasibility study. Dev Med Child Neurol. 2013;55(8):722-8.

2012

Verhoef JAC, Miedema HS, Bramsen I, Roebroeck ME. Using the work limitations questionnaire in patients with a chronic condition in the Netherlands. J Occup Environ Med. 2012;54(10):1293-9.

National publications

Verhoef JAC, Miedema HS, Floothuis MCSG , Van Schaardenburgh N, Stam HJ, Roebroeck ME. Een nieuwe interventie om de arbeidsparticipatie te bevorderen van jongeren met een lichamelijke beperking: een pilot-studie. Wetenschappelijk Tijdschrift voor Ergotherapie 2013;(4):4-18.

Bal MI, Hilberink SR, **Verhoef** JAC, Miedema HS, Roebroeck ME, 2012. *Eindverslag proefimplementatie TraJect aan het werk.* Rotterdam: Erasmus MC/ Kenniscentrum Zorginnovatie.

Verhoef J.A.C., Miedema H.S. & Roebroeck M.E. (2008). TRAJECT: bevordering van arbeidsparticipatie van jongeren met een chronische aandoening. Groningen, Nederlands Congres Volksgezondheid. *TSG jaargang 86 / 2008 nr 2, p. 53*

Verhoef JAC, Miedema HS, Roebroeck ME (2008). Eindverslag Project TRaJect: **T**ransitie naar **A**rbeidsparticipatie van **J**ongeren met **E**en Chronische ziek**T**e. Rotterdam: Erasmus MC/ Kenniscentrum Zorginnovatie.

Klopper R, **Verhoef** JAC. Het ontwikkelen van een evaluatie-instrument voor een interventie. *Nederlands Tijdschrift voor Ergotherapie*, 2007; 35 (7), 29-33.

Van de Woestijne E, Floothuis MCGS, **Verhoef** JAC. MOHO uit de kast! Instrumenten en praktische toepassingen. *Nederlands tijdschrift voor ergotherapie*, 2007; 35(5), 30-33.

Chapters in books

Kuiper CHZ, **Verhoef** JAC, Louw D de, Cox K. 2012. (red.) *Evidence-based practice voor Paramedici. Methodiek en toepassing* (3e druk). Den Haag: Boom Lemma. ISBN: 978-90-5931-8496.

Cox K, Louw D de, **Verhoef** JAC, Kuiper CHZ, 2012. (red.) *Evidence-based practice voor verpleegkundigen. Methodiek en toepassing* (3e druk). Den Haag: Boom Lemma. ISBN: 978-90-5931-8489.

Verhoef JAC, Zalmstra A. Het 'Model of Human Occupation'. In: Van Hartingsveldt M, Le Granse M, Kinebanian A (red.) (2012). Grondslagen van de Ergotherapie (3^{e} druk). Maarssen: Elsevier Gezondheidszorg. ISBN: 978-90-3523-2471.

PhD Portfolio Summary

PHD PORTFOLIO SUMMARY

Summary of PhD training and teaching activities

Name PhD student: Joan AC Verhoef
Erasmus MC Department: Rehabilitation Medicine

PhD period: 2006-2014
Promotor(s): Prof.dr. H.J. Stam
Supervisor: Dr. Marij E. Roebroeck

1. PhD training

	Year	Workload (Hours/ECTS)
Research skills		
- Scholingsdag Praktijkgericht onderzoek, Amersfoort	2014	8 (0.3)
- Workshop Conducting systematic reviews and meta-analyses, Kameshwar Prasad & Regina Kunz, Taormina (2nd Conference of International Society for Evidence-based health care)	2013	4 (0.1)
- Studiedag Praktijkgericht onderzoek in het HBO, Amersfoort	2012	8 (0.3)
- Minicursus Methodologie van patiëntgebonden onderzoek, ErasmusMC	2009	8 (0.3)
- KWALON: Introductie Atlas-Ti	2004	16 (0.6)
- KWALON: Kwaliteit van kwalitatief onderzoek	2004	8 (0.3)
In-depth courses		
- Seminar Achieving Client Centered Practice through the use of the Model of Human Occupation (MOHO), Amsterdam	2009	16 (0.6)
- Symposium 'Kielhofner's Model of Human Occupation', Rotterdam University of Applied Sciences	2006	16 (0.6)
- 2nd Fresenius Symposium on Occupational Therapy: "MOHO – The model of human occupation"	2006	16 (0.6)
Oral Presentations		
- Development of work participation in young adults with CP: a prospective study, Dutch Congress of Rehabilitation Medicine, Rotterdam.	2014	4 (0.1)
- Ontwikkeling van arbeidsparticipatie in jongvolwassenen met cerebrale parese. Presentatie regionaal refereren regio Rotterdam.	2014	3 (0.1)
- Measuring evidence-based practice competencies of occupational therapy students, at 16th International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan	2014	8 (0.3)
- Transition to work of young adults with Cerebral Palsy, at 16th International Congress of the WFOT, Yokohama, Japan.	2014	8 (0.3)
- Interprofessional collaboration in a vocational program, at 16th International Congress of the WFOT, Yokohama, Japan.	2014	4 (0.1)

- Improved work participation and occupational performance of young adults with a physical disability after a new vocational rehabilitation intervention; Leverhulme International Network Symposium, Amsterdam	2014	4 (0.1)
- Review of EBP competency in the curricula of allied health care studies, at 2nd Conference of International Society for EBHC Taormina (Italy)	2013	8 (0.3)
- Changes in occupational performance of young adults with a physical disability entering the labor market, at 9th European Congress of Occupational Therapy, Stockholm.	2012	8 (0.3)
- Preliminary effectiveness and feasibility of an intervention to improve participation in work of young adults with physical disabilities at World Congress on Spina Bifida, Las Vegas (honorable mention)	2012	8 (0.3)
- Occupational performance of young adults with a physical disability: experience in Rotterdam (the Netherlands) with an intervention aimed at improving work participation, at Congress Work for All, International SOFT Federation, Debrecen, Hungary.	2012	8 (0.3)
- Evaluatie van een nieuwe interventie om de arbeidsparticipatie van jongeren met lichamelijke beperkingen te vergroten, refereerbijeenkomst revalidatieartsen Zuid-West Nederland.	2011	3 (0.1)
- Evaluatie van een nieuwe interventie om de arbeidsparticipatie van jongeren met lichamelijke beperkingen te vergroten, jaarcongres ergotherapie.	2011	8 (0.3)
- Young adults with a chronic disorder at work: development and evaluation of an intervention, at15th International Congress of the World Federation of Occupational therapists, Santiago, Chili	2010	8 (0.3)
- Young adult teams: Evaluation of a modular rehabilitation program, at Transitions Pre-Conference Bloorview Kids Rehab, Toronto.	2008	8 (0.3)
- Intervention to improve participation in work. Development, evaluation and implementation, at 8th European Congress of Occupational Therapy, Hamburg.	2008	8 (0.3)
- TraJect: Het ontwikkelen, implementeren en evalueren van een interventie om de arbeidsparticipatie te bevorderen van jongeren met een chronische aandoening, NCVG, Groningen.	2008	8 (0.3)
- TraJect: aan het werk?! Module Arbeidstoeleiding, Transitienet bijeenkomst Rotterdam.	2008	3 (0.1)
- Je bent jong, chronisch ziek en je wilt een baan! Workshop Jaarcongres Nederlandse Vereniging voor Ergotherapie.	2007	8 (0.3)
- TraJect: aan het werk?! Module Arbeidstoeleiding, onderwijsbijeenkomst Polikliniek Jongvolwassenen, Rotterdam	2007	4 (0.1)
International conferences		
- 16th International Congress of the World Federation of Occupational Therapists (WFOT), Yokohama, Japan	2014	32 (1.1)
- Evidence, Governance, Performance - 2nd Conference of International Society for EBHC, Taormina (Italy)	2013	32 (1.1)
- 9th European Congress of Occupational Therapy Stockholm	2012	32 (1.1)

- 15th International Congress of the WFOT, Santiago, Chili	2010	32 (1.1)
- 8th European Congress of Occupational Therapy, Hamburg	2008	32 (1.1)
Seminars and workshops		
- Minisymposium Adults with Cerebral Palsy: Health, wellbeing and implications for treatment. Rijndam Rehabilitation Centre/Erasmus MC	2013	4 (0.1)
- Nationaal Congres Evidence-based Practice, Ede	2012	8 (0.3)
- Workshop Formuleren subsidieaanvragen, ZonMw	2004	16 (0.6)
- Cursus Implementatie ZonMW	2002	24 (0.9)
Didactic skills		
- Afstuderen, verbeteren van ontwerp en toetsing (Hogeschool Rotterdam, Onderwijs en Kwaliteit)	2011	24 (0.9)
Other		
- Member of the supervisory board of the Dutch occupational therapy association (EN)	Since 2013	56 (2.0)
- Reviewer of scientific international journals	Since 2013	28 (1.0)
- Member editorial board Dutch scientific occupational therapy journal	2008-2014	84 (3.0)
- Editor of the books 'Evidence-based practice for allied health professionals' and 'Evidence-based practice for nurses'	2008, 2012	160 (5.7)
- Research meetings, department Rehabilitation Medicine Erasmus MC	2007-2010	42 (1.5)

2. Teaching activities

	Year	**Workload (Hours/ECTS)**
Lecturing bachelor students Rotterdam University of Applied Sciences		
- Bachelor thesis research for occupational therapy students	2011-2014	128 (4.6)
- Evidence-based practice: critical appraisal	2007-2012	144 (5.1)
- Research skills & scientific reasoning	2007-2010	64 (2.2)
- Evidence-based practice: introduction	2007-2010	64 (2.2)
Supervising practicals and excursions		
- Docent cursus afstudeerproject begeleiden voor stagebegeleiders	2012-2014	32 (1.1)
- Supervising bachelor students of allied health professions with minor project	2012	42 (1.5)
- Cursus 'Train de trainers' om de interventie 'TraJect: aan het werk?!' in andere centra te implementeren (Leiden/Den Haag, Amsterdam)	2010, 2012	32 (1.1)

- Invitational conference 'Arbeidstoeleiding van jongeren met lichamelijke beperkingen', Rotterdam University of Applied Sciences	2009	16 (0.6)
Supervising bachelor theses		
- Supervising bachelor theses of occupational therapy students (5 students/year)	2011-2014	160 (5.7)
Other		
- Beroepscompetenties Ergotherapie. Voorzitter landelijke projectgroep om beroepscompetenties ergotherapie te formuleren die dienen als eindkwalificatie voor het bachelorniveau van de ergotherapeut in Nederland.	2010-2013	120 (4.3)
Total		**1629h/ 57.9 ec**


Kaart